PREMATURITY AND DEVELOPMENTAL DELAY.

THE DEVELOPMENT WITHIN THE SECOND YEAR OF LIFE OF A NEW ZEALAND BIRTH COHORT OF PREMATURE INFANTS.

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Table of Contents

List of Tables

TABLE PAGE

List of Figures

Abstract

As a result of progressively improving technology and care procedures in the Neonatal Intensive Care Unit (NICU) the likelihood of a premature infant surviving is increasing. Premature infants' developmental prognoses is improving yet they remain at higher risk of developmental delay than full term infants. The current study assessed the development of 23 children at age 17 and 20 months chronological age uncorrected for prematurity, with gestational ages 32 weeks or less, who were admitted to a NICU and who had recorded selenium values at 28 days of age. The Uniform Performance Assessment System was used in the developmental assessments. Twenty-one percent of the children had a mild or severe developmental delay in one or more developmental areas. These figures were compared with studies from other countries. Eighty percent of children with a disability had a developmental delay and 60% of children with a delay had been re-hospitalised 3 times or more. On average children born prematurely with a developmental delay had had a more severe medical course in the NICU. The Neonatal Medical Index (NMI) was applied to the children's NICU medical records. The NMI risk rating apparently would have predicted which infants would be developmentally delayed at 17 and 20 months of age.

Introduction

"The 'at risk' concept is applied to new-borns and infants whose prenatal development, birth and/or first few months of life have been associated with factors that have high correlation with a disability identified in later life" (Liberty, 1993, p. 9).

Premature birth and subsequent experiences are considered to place premature infants at risk of future developmental delay. Because of improving technology and procedures used in the Neonatal Intensive Care Unit (NICU), a greater number of infants who are smaller and have shorter gestational periods are surviving. Although the majority of children born prematurely are free of major disabilities and developmental delays, the incidence of disabilities and developmental delay in this group is higher than in the population as a whole. As a result of this, emphasis has recently shifted from the mere survival of children born prematurely, to improving their developmental outcome and quality of life.

Developmental delay is socially defined as a development rate which deviates from the average in any one skill domain indicating a slower rate of skill acquisition (Liberty, 1993). Development can be assessed in specific areas and although domains are inter-related, delay in one area does not verify developmental delay in another. Development of skills in young children can be categorised into fine motor, communication (expressive and receptive), self help and social skills as well as gross motor domains. Overseas studies have reported children born prematurely are at risk of developmental delay and even intelligence scores categorised within the population's average are more likely to be lower for children born prematurely than that of full term controls (Rickards, Kitchen, Doyle, Ford, Kelly & Callanan, 1993) and were more likely to repeat a school year. Mild delays may only become apparent when specific skill areas are assessed and looked at separately. One example is visual perceptual knowledge. In one study, children born prematurely, on average, did not perform as well as full term children in copying shapes and figures (Klein, Hack & Breslau, 1985). This fine motor skill is essential in learning to write and children who learn this skill

later may become frustrated in their school tasks possibly resulting in academic failure (Klein, Hack & Breslau, 1985). The early recognition of developmental delays in children born prematurely can result in enrolling these children to appropriate intervention groups to assist in their developmental catch-up and preventing possible future developmental delays.

There is little New Zealand follow-up of children born prematurely or of the incidence of disabilities and developmental delay in this group. The current study intended to measure the development of a cohort of children born prematurely. Their NICU medical records, medical records since discharge which were relevant to their premature beginnings and relevant life events were summarised and examined along with their rate of development.

Literature Review

Prematurity

Definition

Premature or pre-term refers to infants born at or before 36 weeks gestational age. Low birth-weight (LBW) applies to infants who weigh below 2500 grams at birth, very low birth weight (VLBW) infants weigh less than 1500 grams at birth and extremely low birth weight (ELBW) refers to infants with birth weights less than 1000 grams. The number of ELBW infants are increasing as survival rates within this weight range are improving. As the medical knowledge and neonatal care is improving, the outcomes of heavier premature infants are improving and some medical and outcome factors may now be more relevant to ELBW infants where once they frequently occurred at other birth weights (MacArthur & Dezoete, 1992).

The category of LBW infants can also be categorised when considering gestational age. The infant's weight at birth may be appropriate for gestation age (AGA), that is within the statistically average weight range for their gestation age, or small for gestation age (SGA), below the tenth percentile for their gestation age and they may have been born at term or prematurely. For example, an infant born at 35 weeks and weighing 2250 grams is considered premature but AGA. An infant weighing the same at birth but born at term would, however, be considered SGA (Batshaw & Perret, 1992; MacArthur & Dezoete, 1992). Infants with the same birth weights yet with different gestational ages may also differ in their susceptibility to medical complications. An infant who is SGA will be more mature physically dispite their size and are less likely to suffer from the same complications as a premature infant of the same weight but AGA. For example a SGA infant's lungs are more developed and respiratory problems that infants of the same weight yet shorter gestational age are susceptible to may not be as much of an issue for the SGA infant. Therefore knowing the infant's gestational age as well as their birth weight is also important in their medical care and in research.

Incidence

The incidence of premature birth is between 5-7% of all live births in Western countries (Zahr, Parker & Cole, 1992; Cohen, 1986; Piekkala, Kero, Erkkola & Sillanpaa, 1986). There is some evidence of racial and socio-economic disparity. Black Americans are more likely to give premature birth (13%) than White Americans (6%) (Baumiester, Kupstas & Klindworth, 1990). Such a racial disparity does not appear to exist in New Zealand when examining the number of infants born with birth weights less than 1500 grams and their ethnicity (Table 1). A higher rate of premature birth has also been recognised in the lower socio economic classes in the United States of America. Low socio economic status (SES) mothers were 50% more likely to have an infant born prematurely than middle or high SES mothers (Zahr, Parker & Cole, 1992).

Table 1.

Rate of Births Less Than 1500 Grams per 1000 Live Births, Divided by Ethnic Group in New Zealand, 1992 (Ministry of Health, 1994).

Ethnic Group	**Births <1500 grams/ 1000**
Maori	9.1
Pacific Islanders	6.8
European	9.6
Average	9.3

Causes

Although premature birth may be viewed as the source of current and future problems, it is also a symptom or an outcome of previous events, hence it is possible that both the premature birth and the infant's later development can be traced to a prior underlying problem (Goldberg & DiVitto, 1983). Although in the majority of cases, the

cause of premature birth can not be identified, there appears to be several distinct risk factors. Premature birth has been associated with:

- *low socio-economic status (SES).* Probably because multiple contributing factors are more likely to co-occur in this group, such as inadequate prenatal medical care, adolescent pregnancy and poor nutrition (Zahr, Parker & Cole, 1992),
- *maternal complications during pregnancy.* For example, diabetes, high blood pressure and infections (Batshaw & Perret, 1992),
- *premature rupture of the amniotic sac surrounding the foetus* (MacArthur & Dezoete, 1992),
- *multiple pregnancies.* Twins make up 1% of total births, yet 10 % of preterm births (Piekkala, Kero, Erkkola & Sillanpaa, 1986),
- *maternal smoking* (Witter, 1993),
- *substance or alcohol abuse* (Witter, 1993),
- *prematurity as an outcome of a prior problem.* Cerebral palsy may result from premature birth, or cerebral palsy may be traced to prior to the premature birth. One third of children with cerebral palsy and 59% of children with diplegia were born preterm, 12% of VLBW infants have spastic cerebral palsy (Batshaw & Perret, 1991),
- *adolescent pregnancy.* Particularly so if the mother is under the age of 15 years old. Teenage pregnancy makes up only 5% of all pregnancies yet accounts for 20 % of premature births (Batshaw & Perret, 1992). In New Zealand during the five year period from 1988-1992, teenager mothers accounted for 8% of all live births but 12% of all births less than 1500 grams (Ministry of Health, 1994).

No one factor appears to have a good predictive value of prematurity.

Mortality Rate

Up until recently, approximately 70% of premature infants weighing less than 1500 grams at birth and up to 90% of infants born less than 1000 grams at birth died during the new born period (Batshaw & Perret, 1992). Of those infants who did

survive, the likelihood of the child having a disability or having a developmental delay was high.

The three leading causes of infant mortality in New Zealand in 1991 can be related to low birth weight or deaths from which premature infants appear to be at high risk (Table 2).

Table 2.

Leading Causes of Death for Infants in New Zealand in 1991,

(New Zealand Health Information Service, 1994).

Cause of Death	**Male** (% of total deaths)	**Female** (% of total deaths)
Sudden Infant Death Syndrome	29	26
Respiratory Distress Syndrome	10	6
Extreme Immaturity	6	9

Infants defined as children aged 1 year of age or below (New Zealand Health Information Service, 1994).

Increasing Survival Rate

As prenatal, peri-natal and postnatal medical care improves, so too do the chances of premature infants' survival. The current survival rate of premature infants born weighing between 1000-1500 grams at birth is 90%, over 60% of infants weighing 750-1000g at birth survive and one third of infants weighing 500-750 grams survive the neonatal period (Rickards, Kitchen, Doyle, Ford, Kelly & Callanan, 1993; Hack, Horbar, Malloy, Tyson, Wright, & Wright, 1991; Grogaard, Lindstrom, Parker, Culley & Stahlman, 1990). In New Zealand the survival rate of VLBW infants was 73% (Crombie & Darlow, 1986) and in 1991 the survival rate of LBW infants was 91%, and 95% of infants born at or before 30 weeks gestational age lived (Table 3).

Table 3.

Rates of Survival by Gestational Age and Birth Weight in New Zealand 1991 (New Zealand Health Information Service, 1994).

Gestational Age (Weeks)	**Survival Rate** (%)	**Birth weight** (grams)	**Survival Rate** (%)
< 30	95	< 2500	91
30-34	99	2500-3499	99
35+	99.5	3500 +	99.8
Total	99.5	Total	99

With improving technology and medical care, concern for the majority of premature infants has now shifted from survival to the effect prematurity has on subsequent development and outcomes (Emory, Savoie and Toomey, 1990).

Disabilities

Incidence

Although medical knowledge and technology and neonatal care is continually researched and updated to improve the survival and outcomes for pre-term infants, these infants still have a higher incidence of disabilities than do full term infants. Initially, the rate of children born prematurely with a disability decreased with the improving technology. However, as more infants with shorter gestational ages and lighter birth weights are surviving, who are more likely have a disability or have a medical course which may result in a disability, the prevalence of disabilities in premature infants may not be decreasing as rapidly (Graeber & Schwartz, 1993).

A follow up at 8 years of age of children who were born prematurely reported that 18% had a severe disability, compared with 3% of the general population (Victorian Infant Collaborative Study Group, 1991) and 6% had moderate disabilities (Elliman, Bryan & Elliman, 1986). Disabilities are more prevalent in children with lower birth weights and shorter gestational ages.

Studies of children with birth weights less than 1500 grams have reported the incidence of cerebral palsy between 2-18% (Victorian Infant Collaborative Study Group, 1991; Teplin, Burchina, Johnson-Martin, Humphry & Kraybill, 1991; Saigal, Szatmari, Rosenbaum, Campbell & King, 1990; Klein, Hack, Gallagher & Fanaroff, 1985; Coolman, Bennett, Sells, Swanson, Andrews & Robinson, 1985; Hunt, Tooley & Harvin, 1982). The incidence of cerebral palsy in the total population is approximately 2 per 1000 people (Paneth, 1986). One New Zealand study reported 7% of VLBW children had a mild or moderate handicap and 6% had a major handicap (Crombie & Darlow, 1986).

Hearing and vision problems may not be evident at the time of discharge from the NICU. Six percent of children with birth weights less than 1500 grams in one study had hearing loss and 12% had vision impairment (Victorian Infant Collaborative Study Group, 1991). A number of children born prematurely may have multiple disabilities (Victorian Infant Collaborative Study Group, 1991; Elliman, Bryan & Elliman, 1986).

Developmental Delay in Premature Infants

Definition

A normal developmental path is defined by the culture as the acquisition of socially desirable skills as set out by society within an average age span (Liberty, 1993). Deviations from the societal norm, especially slower rates of achievement, are a cause for concern in many cultures. If the child does not perform the average number of skills expected for their chronological age, they are identified as having a developmental delay. The greater the deviation from the social expectations, the more severe the developmental delay is considered to be (Liberty, 1993). Formal assessment methods are not perfectly reliable given individual differences, however, many instances of severe developmental delay are evident by 12 months, milder degrees of developmental delay by 36 months of age and learning disabilities become apparent during the first three years of formal schooling (Liberty, 1993).

Incidence

As a function of their immaturity, the medical treatments needed to save their life and environmental factors, the premature infant is at risk of developmental delay. The reported incidence of developmental delay for children born prematurely vary with different criteria used for participation in the study, the instrumentation, definition of developmental delay and the aspects of development investigated. The incidence of severe developmental delay (developmental rates 3 standard deviations below the average) has been reported at approximately 6% of children born prematurely (Smith, Ulvand & Lindemann 1994) and 17%-29% of children born prematurely had developmental rates indicating mild developmental delay (below 2 standard deviations below the average; Ramey et al., 1992; Infant Health & Developmental Program, 1990). In one study 21% of the VLBW children had an intelligence score below 85 (1 standard deviation below the average) at 8 years of age (Hack, Breslau, Aram, Weissman, Klein & Borowski, 1992). Learning problems are generally estimated at 3-7% for the total population (Lewis, 1986). Klein, Hack and Breslau (1989) followed-up the development of VLBW children at 9 years of age. All the children had intelligence scores within the average, yet 40% of the VLBW children had repeated a school year compared to 11% of the children born at term.

Difficulties arise when comparing reported incidence of developmental delay as the premature infant population can not be studied as a homogeneous group. Children born prematurely who have their development followed may differ greatly in

- *gestational age*
- *birth weight*
- *medical complications*
- *medical technology that aided the infant*
- *subsequent life experiences*
- *socio economic status*
- *whether they had a disability.*

In general, the incidence of developmental delay increases in children of lower birth weight and shorter gestational ages and in groups of children who experienced more severe and a greater number of medical complications during the neonatal period.

Premature infants initially thought free of any neurological deficits and who have early intelligence scores within the population's average range are thought possibly still at risk of subtle developmental delays such as learning problems which may not become apparent until they begin formal schooling or until specific skills, such as fine motor, are assessed (Klein, Hack & Breslau, 1989; Klein et al., 1985).

Correcting Age for Prematurity in Calculations of Development

In calculating the rate of developmental of a child born prematurely one of two ages can be used to determine whether development is on track. The child's chronological age (uncorrected) may be compared with their developmental age, or the number of weeks the child was born premature may be subtracted off their chronological age (corrected age) before comparing with the child's developmental age. Correcting the child's age for prematurity is used as it is believed that children born prematurely do not experience a developmental delay rather a developmental lag and once the child's age is adjusted for prematurity the apparent developmental delay disappears (Goldberg & DiVitto, 1983). If the use of corrected age is continued beyond a stage when 'catch up' of development has been achieved or could have been achieved, real problems or delays may go undetected and an overestimation of the child's abilities may result (Kalamar and Boronkai, 1991; Holmes, Reich & Pasternak, 1984). It is agreed correcting age in calculations of developmental achievements should not be continued after 24 months of age (Batshaw & Perret, 1992).

Previous research

Studies of children born prematurely have concluded that there is an increased incidence of developmental delay in comparison to their full term peers, even when the data of children with obvious neurological deficits are excluded from the analysis. Rickards and colleagues (1993) found that although the mean developmental age (the

number of skills passed by the child is compared to a population average age of rate of skill acquisition) of the children born prematurely was considered within the average, it was considerably lower than the mean developmental age of children born at term.

When specific skill areas are tested, children born prematurely tend to perform less well than full term control children. One study suggested they may have visual perceptual difficulties at age 5 years and be poorer copying figures or designs or replicating shapes when drawing (Klein, Hack & Breslau, 1985). Visual perceptual knowledge is important for reading and writing and delays in this areas could lead to frustration and failure in school work (Klein, Hack & Breslau, 1985).

Children born prematurely have also been reported to have had delays in language comprehension and expression and this language delay at 3 to 5 years of age was associated with significantly higher prevalence of reading difficulties at age 7 years (Silva, McGee & Williams, 1983). Although socio-economic status was found to be significantly associated with the language development of healthy full term children, adverse peri-natal events, birth weight, gestational age and a poor score on a peri-natal optimality test were better indicators of language development in the preterm child (Largo, Molinari, Comenale, Pinto, Weber & Duc, 1986).

Kalamar and Boronkai (1991) followed the development from birth to 7 years of age of a cohort of preterm infants (gestational age 29-37 weeks) who weighed 1000-2500 grams at birth, and compared their development with that of full term children. Children with neurological deficits and severe disabilities were excluded from the study to examine the effect prematurity alone had on development. Kalamar and Boronkai found that differences between children born preterm and full term were apparent very early in the infant's lives. Responses to human voice and pre-verbal vocalisation were delayed in the premature infant and full term children significantly out performed their prematurely born peers on the Binet Intelligence Quotient (IQ) assessment at 3, 6 and 7 years of age. Only at 4 years of age, did the children born prematurely experience apparent 'catch up' in IQ with their full term counterparts and at 5 years of age they performed better in the assessment than full term children. This may have resulted from an over estimation of the child's abilities as all developmental calculations used

the child's age corrected for the number of weeks they were born premature. It was postulated that the lower IQ score at 3 years of age may have been a function of attention deficit rather than an intellectual deficit as there were difficulties with children born prematurely completing the assessment.

A second longitudinal study following the development of children born prematurely is the Vermont Intervention Program (Achenbach, Howell, Aoki & Rauh, 1993; Achenbach, Phares, Howell, Rauh & Nurcombe, 1990; Rauh, Achenbach, Nurcombe, Howell & Teti, 1988). The Vermont study compared the development of premature infants involved in the Vermont early intervention program with two comparison groups, premature infants not involved in the early intervention program (control group) and full term normal birth weight peers (contrast group).

The development of all children was assessed at 6 and 12 months and 2, 3, 4, 7 and 9 years. Data of children with congenital anomalies and severe neurological defects were omitted from analysis so as to investigate the effect prematurity had on development.

The children born prematurely who did not participate in the early intervention program scored lower than the full term children at each assessment. The academic achievement of the non-intervention children fell increasingly further behind that of both the other groups and by age 9 years old, approximately half of the children born prematurely had been retained a grade in school for academic reasons. Although the premature children had no obvious delay, they were functioning at a lower cognitive level than that of their full term peers from an early age. Children involved in the Vermont Early Intervention Program were performing on par in all areas from the age of 3 years old when 'catch up' was achieved with the full term children (Achenbach et al., 1990, 1993; Rauh et al., 1988).

The premature infant who does *not* experience early intervention may be delayed in reaching developmental milestones, although the delay may only become apparent over time.

Factors of Prematurity Associated With Developmental Delay

In many cases it is not known what factors place the premature infant at risk of developmental delay. It is possible that because of their early emergence in to the world and that their body and central nervous system are not prepared for extra-uterine life developmental delay may result, or because the early environment of the premature infant is very different to that of healthy full term babies. The early environment of premature infants is the Neonatal Intensive Care Unit (NICU), where the premature infant may spend much of their first year of life.

The Neonatal Intensive Care Unit

Description. The NICU deploys three types of equipment. During their stay in the NICU the premature infant's immediate environment is the incubator. Sensory stimulation may distorted because of this environment. Sounds, for example, may be muffled and at the same time may be echoed because of the incubator. A second system keeps track of bodily functions such as heart rate, breathing, body temperature, blood oxygen and lets staff know if and when the infant needs assistance and the third system assists or carries out body functions when the infant cannot do so alone. This may consist of assisting breathing by pumping oxygen into the incubator or through a respirator (tube to the lungs); food, vitamins and medicine may be given directly into the veins, or the infant may be fed through a naso-gastric tube (small tube inserted through their nose to assist milk to reach their stomach) as the sucking and swallowing reflexes are weak. The infant's eyes are covered if a lamp is used to treat jaundice. The light helps to break down a substance produced as old red blood cells are destroyed (bilirubin) when the liver is not mature enough to do so (Holmes, Reich & Pasternak, 1984). The preterm infant may need blood transfusions to replace blood extracted for daily tests. The temperature within the incubator is controlled as premature infants have little regulation of their own body temperature.

The ratio of nurses to infants in the NICU is high, usually one to one. Once the infant has stabilised medically, they are moved into an intermediate care nursery to put on weight and grow before they are discharged.

NICU Stay. The time spent in hospital for premature infants often extends beyond the child's due date with the pre-term infant often taking 2 to 3 weeks to stabilise before they begin to put on weight and grow (Batshaw & Perret, 1992). The hospital stay for a 1000-1500g infant may be 2-3 months (Usher, 1987). In New Zealand the premature infant's average hospital stay was 20.4 days in 1992, compared to 3.5 days for healthy full term infants (New Zealand Health Information Service, 1993).

Transportation. Because of the expense of the equipment in the NICU, units are centralised. New Zealand NICUs are in Dunedin, Christchurch, Wellington, Hamilton and Auckland. This can mean the transportation of some infants and their mothers to distant hospital centres where there may be little available emotional and physical support. Visits from family members may be limited because of the distance involved and family members may have to return home because of family and work demands there.

Infants transported to a NICU have been reported at greater risk of adverse outcomes than infants born in a hospital with a NICU. McCormick, Stemmler, Bernhaum and Farren (1986) reported 17% of children born prematurely and transported to the NICU were re-hospitalised in their first 4 years of life, compared with 8% re-admission of all under 6 years of age in America. In New Zealand infants who were transported to the NICU were at greater risk of respiratory problems, periventricular haemorrhage and neuro developmental outcomes than premature infants born in the hospital with a NICU (Harding & Morton, 1993).

Treatments provided. Many conditions, together or individually, result in the LBW infant's admission to the protective environment of the NICU.

Because of their immaturity, premature infants do not have the fat reserves of full term infants and as a result body heat is lost more rapidly (Batshaw & Perret, 1992) and the infant cannot regulate and control their body temperature. If body temperature is not controlled the infant will develop apnoea, hypoglycaemia (low blood sugar reserves, resulting in lethargy and vomiting) or acidosis (acidity of body fluids and tissues is abnormally high), all of which can be life threatening (Batshaw & Perret,

1992). In the NICU the infant is placed in an incubator, in which a constant temperature is maintained. The artificial environment of the NICU including the constant temperature, minimal light differentiation between night and day and noise and light levels greater than normal, may result in the premature infant habituating to their surrounds which may be carried through to interactions in environments outside the NICU and with their parents and significant others. The premature infant may appear unresponsive and difficult to arouse (Cohen, 1986). This may contribute to developmental delay.

Preterm infants may have feeding difficulties because of the under-development of sucking and swallowing reflexes (Brake, Fifer, Alfasi & Fleishman, 1988). In the NICU, a naso-gastric tube to the stomach may be used to supply the premature infant with nutrients and food. If this is not possible, nutrients must be supplied intravenously but exact nutrient requirements of the premature infant are not known and the infant may receive insufficient nutritional supply for growth (Holmes, Reich & Pasternak, 1984). Mothers may be encouraged to provide breast milk as it is easier for the baby to digest and it carries antibodies that protect the infant from infection (MacArthur and Dezeote, 1992). The infant will remain in the NICU until they can feed satisfactorily and have gained sufficient weight. Interactions between parents and the infant such as holding, feeding and playing are restricted during the infant's time in the NICU because they are in an incubator and are connected to tubes for feeding.

Infants born prematurely have a higher incidence of developing breathing problems resulting from the under-development of their lungs at birth. These problems include respiratory distress syndrome, bronchopulmonary dysplasia, retinopathy of prematurity and apnoea.

Respiratory distress syndrome (RDS) develops because the premature infant lacks sufficient surfactant to coat their lungs and without this lining the infant is unable to keep their lungs inflated after each breath. This results in breathing difficulties and possibly collapsed lungs (Hansen & McClead, 1990). The incidence of RDS in premature infants is associated with gestational age as it is related to the maturation of the lungs. In infants born at 23 to 24 weeks gestation, the incidence is greater than

90%, declining to approximately 60% at 28 weeks, 30% at 32 weeks and to less than 5% at 36 weeks gestational age (Gleason & Durand, 1993). Treatment in mild cases may consist only of a mixture of air and oxygen fed into the incubator. In other cases, natural or artificial surfactant may be delivered via a tube to the lungs to assist in keeping airways and lungs open and to ameliorate the course of RDS (Hansen & McClead, 1990; Batshaw & Perret, 1992). In addition, the infant may be placed on a mechanical ventilator to assist breathing. The infant may require two short tubes placed into their nose to provide sufficient oxygen and the most severely affected infants have a tube to the lungs (intubation) to provide a more direct source of oxygen and air (Batshaw & Perret, 1992).

The treatment of RDS can lead to chronic lung disease called bronchopulmonary dysplasia (BPD). BPD occurs in approximately one third of infants who required mechanical ventilation and is a reaction to damage from the oxygen and pressure (Thorp & Raver, 1991). BPD occurs when the walls of the immature lungs thicken and the capacity of the lungs and the airway diameter is greatly reduced, making the exchange of oxygen and carbon dioxide more difficult (Batshaw & Perret, 1992). In treating BPD oxygen therapy, artificial ventilation and the use of bronchodilators and diurtetics (prevents fluid build up) are used to keep airways open and the lungs 'dry', but, BPD may continue for months or years post discharge and children who suffered from BPD may have a low tolerance of exercise and a high re-hospitalisation rate as long term health problems continue (Batshaw & Perret, 1992; Hansen & McClead, 1990).

Apnoea, a third breathing problem, is the cessation of breathing for 20 seconds or more which is frequently accompanied by bradycardia, a fall in heart rate (Batshaw & Perret, 1992; Thorp & Raver, 1991). The more premature the infant, the more likely and frequently apnoea attacks are to occur. Approximately 10% of all premature infants suffer from apnoeic episodes, however over 40% of VLBW infants have apnoeic episodes (Usher, 1987). As the child matures the severity and frequency of apnoeic episodes tend to decrease. While there is no current preventative apnoea treatment infants who suffer from apnoea, or who are at risk, can be monitored by a

cardiorespirator monitor that sounds an alarm if the infant stops breathing. Some infants need only tactile stimulation to start breathing again while others will require cardiopulmonary resuscitation. Once the infant is discharged from the NICU they may be re-admitted to hospital because of apnoeic attacks. Breathing problems experienced by premature infants may be associated with developmental delay because they may disrupt the infant's experiences in the environment and with important persons within the environment.

The premature infant admitted into the NICU for breathing problems can be exposed to further medical complications as the oxygen provided can catalyse tissue damage. Retinopathy of prematurity (ROP), which in it's most extreme form results in blindness and intraventricular haemorrhage (IVH) are two severe outcomes from oxygen use.

ROP may affect the development of children born prematurely if it results in vision impairment or blindness. The retina in the eye is one of the last structures in the eye to mature before birth. When the premature infant is born the retina may not be sufficiently developed and as a result of its exposure to an environment which it is not prepared, the retina may develop abnormally. The terminology for this is retinopathy of prematurity (ROP). There are varying degrees of ROP, from minimal acute changes in the retina (grade I & II), more severe retinal arteriovenous shunts (grade III), to detachment of the retina causing blindness (grade IV). In 80% of the cases in which the premature infant develops ROP the eye heals itself (Thorp & Raver, 1991). Retinal tears can be treated with cryotherapy or laser therapy to prevent retinal detachment (Hansen & McClead, 1990) and in many cases if vision impairment persists, it can be corrected by the child wearing glasses.

Fifteen percent of infants weighing less than 1251 grams at birth are diagnosed with ROP (Graeber & Schwartz, 1993). It is now known that excessive levels of oxygen once provided to infants for RDS catalysed the damage of tissue resulting in ROP (Vohr & Garcia-Coll, 1988). The provision of oxygen has since been cut back and is currently well monitored. However since ROP has not disappeared it is believed that it's a function of gestation age, with increasing incidence of ROP associated with

shorter gestation periods (Graeber & Schwartz, 1993; Urrea & Rosenbaum, 1989). The rate of ROP has remained fairly constant over more recent years despite an initial decrease with increased knowledge of ROP and the improved treatment of premature infants. This is probably because of the increase in number of infants surviving with shorter gestation ages (Graeber & Schwartz, 1993; Valentine, Jackson, Kalina & Woodrum, 1989).

Another problem that may occur during the infant's first few days is intraventricular haemorrhage (IVH). Premature infants have a fragile network of blood vessels that supply the brain. While still developing these vessels are especially sensitive to changes in oxygen and pressure. This seems especially so during the first two days of life when IVH if it does occur will be diagnosed. IVH is diagnosed as blood vessels in the brain bleeding and the severity of IVH is graded according to the amount of bleeding and the different parts of the brain affected (Volpe, 1990). The prognosis of IVH is associated with the extensiveness of bleeding and the part of the brain affected. Small bleeds once went undetected because of unobservable symptoms, but can now be detected using computerised tomography (CT) or cranial ultra sound (Vohr & Garcia-Coll, 1988). Small bleeds are common in premature infants and are often asymptomatic (grades I & II) and developmental prognosis appears similar to VLBW infants without IVH. In one study, major handicaps was reported 9% of children with grade I IVH and 11% of children with grade II IVH (Sosteck, 1988). More extensive bleeds are graded III or IV and these children are more likely to have a major handicap (58% have major handicaps) (Sosteck, 1988). Grades III and IV are associated with abnormal muscle tone and an increased risk of cerebral palsy and spastic diplegia (Graziani, Pasto, Stanley, Pidcock, Desai, Desai, Branca & Goldberg, 1986).

Nearly half (47%) of infants who weighed less than 1500 grams at birth develop IVH (Bozynski, Nelson, Rosati-Skertich, Genaze, O'Donnell & Naughton, 1984). The chance of IVH occurring decreases in infants with longer gestational age and heavier birth weight (Volpe, 1990; Bozynski et al., 1984). No definite effective treatment is

currently available for IVH and prevention still appears to be the best method (Ichord, 1993).

Selenium. New Zealanders, particularly in the South Island, have one of the lowest levels of selenium in the world, which reflects the little available selenium in their diet. This is also the case in infants because of low selenium availability and uptake in the womb followed by inadequate dietary supply of selenium (Dolamore, Brown, Darlow, George, Sluis & Winterbourne, 1992). Selenium status in premature infants is thought to be an essential component of the body's natural defence against oxidative tissue damage which can result in BPD, IVH and ROP, to all of which the premature infant is particularly susceptible (Sluis, Darlow, George, Mogridge, Dolamore & Winterbourne, 1992).

Infants (both full term and preterm) admitted to the NICU have been reported to have significantly lower selenium levels than healthy full term infants (Sluis et al., 1992). A Christchurch study (Sluis et al., 1992) recorded selenium levels of infants admitted to the NICU. The 12 infants with the lowest selenium values had poorer medical diagnoses. Two thirds still required oxygen at 28 days of age. Of this group, 75% had evidence of BPD and there was a 42% incidence of ROP and 42% had an abnormal cranial scan.

A second issue of selenium is it's possible association with Sudden Infant Death Syndrome (SIDS). SIDS is defined as finding an infant not breathing after they were healthy when put to bed (New Zealand Health Information Service, 1994).

Infants who suffer from apnoeic attacks, which the premature infant is at high risk of, are at higher risk of SIDS (Goyco & Beckerman, 1990). Children with birth weights of 2500 grams or less were two and a half times more likely to die of SIDS than infants born weighing 3500 grams or more at birth and two times more likely than infants born weighing 2500-3499 grams at birth (Table 4; New Zealand Health Information Service, 1994).

Dolamore and colleagues (1992) examined selenium levels of full term infants and infants who were victims of SIDS. Full term infants who were breast fed had higher selenium values than those bottle fed. Comparisons of selenium status of full

term infants and SIDS victims showed selenium values to be significantly lower in the SIDS group than the breast fed group. There was no significant difference in selenium values between the SIDS group and the bottle fed group or the sample as a whole.

Although Dolamore and colleagues (1992) did not make any conclusive connections between selenium values and SIDS, they did report

> *"• SIDS rate is higher and selenium status is lower in the South Island than the North Island in New Zealand,*
>
> • *formula fed babies have lower selenium levels and are at higher risk of SIDS, and*
>
> • *preterm infants have lower selenium levels and a higher rate of SIDS"* (Dolamore et al., 1992, p. 142).

Table 4.

Rate of Death by Sudden Infant Death Syndrome of Infants Less Than 1 Year Old, Broken Down by Gestation and Birth Weight, New Zealand, 1991.

(New Zealand Health Information Service, 1994).

Birth weight (grams)	**Rate of SIDS** (per 1000 live births)	**Gestational Age** (weeks)	**Rate of SIDS** (per 1000 live births)
< 2500	4.4	<30	2.7
2500-3499	2.6	30-34	4.2
3500+	1.5	35-37	4.4
		38-39	2.4
		40+	1.8
	Average = 2.4		**Average = 2.4**

Rates per 1000 live births.

It is not known whether selenium status is at all associated with the development of the child born prematurely once they are discharged from the NICU.

Parent-Child Interaction at Birth

Behaviours between parent and infant are reciprocal and the infant reinforces and shapes the parent's behaviour and vice versa. From birth all those behaviours and characteristics observed in the infant help determine the stimulation she or he receives and the interaction between the parent and child may be affected in a number of ways because of the infant's early beginnings and subsequent experiences.

Parents' beliefs about the premature infant, formed during the neonatal period, may continue beyond the neonatal period even if they are inappropriate. For example, the belief that their child is fragile, although true during the peri-natal period may not be the case at school age. Parents may continue to 'protect' their child from experiences and environments which they believe may result in harm or illness. As a result the child's age-appropriate behaviour may not be reinforced and parents may not feel reinforced in their parenting role. Behaviours which are not reinforced will eventually be omitted from their behavioural repertoire and may be substituted with less appropriate behaviour, possibly leading to behavioural problems and learning difficulties.

Many early intervention programs recognise the importance of good parent infant interactions. Studies have reported that improved parent-child interactions had lasting benefits through to at least 9 years of age (Achenbach et al., 1990, 1993; Rauh et al., 1988). Children whose parents received help in interpreting and improving parent-child interaction performed significantly better in several areas than children whose parents did not receive this help (Achenbach et al., 1990, 1993; Rauh et al., 1988) and parents reported greater satisfaction from their parenting role than those parents who did not receive assistance in interpreting their child's behaviours (Amick, 1989). Mothers who had received help and encouragement during the infant's NICU period held their baby more often and were more likely to be involved in the infant's feeding routine (Amick, 1989).

The premature delivery is a time of crisis for parents. They may be unsure of what is exactly happening and whether their infant does have a chance of living. Medical staff need to work fast to improve the chances of the infant's survival and their

outcomes. The infant may need to be resuscitated and the parents may not get to see, hold or spend any time with their infant before the infant is taken away to the NICU. Mothers may also have medical complications from the premature birth and it may be days before she can be moved to the same hospital as her child if the infant has been transported. This move may result in the separation of families for a period of time if the hospital is some distance from their local region and emotional support for parents of the preterm infant may be difficult because of the distance from family and friends. The father and other family members may have their time divided between the mother and the infant or may remain in one hospital sending or receiving updates of their child's or the mother's progress by telephone. The birth of a preterm baby can be a traumatic experience, leaving parents with many different emotions: guilt having produced a small; sick infant; mourning the loss of the baby they were expecting; anxiety about whether their child will live, and if they do survive, what the prognosis may be. Some parents may respond to the premature birth by detaching themselves from the infant in case their child does not survive or becoming highly anxious (Amick, 1989).

The premature infant may look and behave differently to their full term peers because of their immaturity and early life experiences, which consequently may arouse emotions affecting parents' perceptions of their child and therefore parent-child interactions. In fact, the first view of their baby might be of their new-born in an incubator attached to various monitors and tubes. More differences are also evident. Premature infants are not fully physically developed which is most obvious in their small size. The premature infant is skinny with little body fat and has little muscle tone (Batshaw & Perret, 1992). Depending on the child's gestational age, some external organs may not be fully developed such as the ear cartilage and breast buds which form later during gestation and their skin may appear opaque and reddish as the blood vessels are closer to the surface (MacArthur & Dezoete, 1992; Holmes, Reich & Pasternak, 1984). The premature infant may also be covered in fine body hair, which is lost at approximately 38 weeks gestational age (Batshaw & Perret, 1992).

Thus the premature infant has few of the 'baby like' features that many expectant parents would have anticipated, she or he is not the bouncy big baby they may have prepared for and feelings of inadequacy and fear may be aroused as a result of their child's appearance, possibly affecting initial feelings toward their child (MacArthur & Dezoete, 1992; Holmes, Reich & Pasternak, 1984). Some of their child's physical characteristics may cause the parent to respond in a more negative manner towards their child than if they were full term, such as the infant's muscle tone affecting the way the parent holds their child. It is also possible that this and other physical characteristics such as the small size of their child and fear of their child's survival especially in the early stages, cause the parent to not want to become too attached to their child and even naming their child may take a longer time than if the child was full term (Holmes, Reich & Pasternak, 1984). Parents may not feel reinforced as a parent since they have not produced a child that looks like the children of friends and family members (Holmes, Reich & Pasternak, 1984).

The preterm infant's early experiences and environments are very different from those of most healthy full term infants. Instead of cuddles and being cared for by doting parents, they are enclosed in an incubator and bombarded with noises and lights and the day to day routine is taken care of by medical staff. The noise in the NICU may interfere with the way the infant processes sounds (MacArthur & Dezoete, 1992) and hearing loss may occur which in turn can lead to language delay (Silva, McGee & Williams, 1983). These and other NICU experiences may hinder development because of the disruption to a normal daily routine and contact with parents.

Preterm infants may be physically over stimulated and contact especially for the sickest, smallest child may be very unpleasant. Negative contact (e.g. injections and blood tests) may well greatly exceed 'positive' contact. Gottfried and colleagues (1981) reported that only 0.02% of the NICU infant's day was taken up by social touching (5.8% of day for infants in intermediate care) and 15.5% of the day involved medical or nursing care (3.8% of the day for infants in intermediate care). This type of physical contact is thought can result in the infant habituating to stimulation and becoming difficult to arouse, therefore, limiting learning opportunities that may arise

(Robinson & Jackson, 1991). In comparison to healthy full term infants who have one main caregiver (usually the parent) the premature infant has several caregivers and the longer they are in the NICU the more care givers they will encounter. As a result parents may feel some resentment towards their child's carers and powerless in helping their child (MacArthur & Dezoete, 1992; Holmes, Reich & Pasternak, 1984). By the time the infant leaves the hospital parents may not be confident in their own abilities to look after their child (Holmes, Reich & Pasternak, 1984).

Parent-Child Interaction During the First Few Weeks at Home

Once home, factors about the preterm birth continue to affect parent-baby interactions. The belief their child is fragile or delicate, even if the reality is different, may modify the experiences and environments parent's allow their child to participate in. Because children learn new skills from their experiences in different environments and from people they interact with, limiting experiences may slow the rate of acquisition of skills (Cohen, 1986; Holmes, Reich & Pasternak, 1984).

In the first 6 months after birth, the premature infant sleeps for longer periods than full term infants (Holmes, Nagy, Slaymaker, McNeal & Gardner cited in Holmes, Reich and Pasternak, 1984. p. 110). Infants with gestational ages of 28-36 weeks sleep on average 21.5 hours (88%) of the day compared to full term infants who slept on average 18 hours (77%). If the child sleeps most of the time they are not available to explore the environment and participate in new experiences.

Als, Duffy and McAnulty (1988) reported that preterm children found it difficult getting to and maintaining a 'steady focused alert state', as once they were stimulated they easily became over stimulated. As a result of this parents may not feel reinforced and indeed may feel punished, for exposing their child to new experiences and environments as this may result in a distressing experience for the child and their parents (Als, Duffy & McAnulty, 1988). The most responsive state for learning is alert inactivity, however the preterm infant spends less time in this state than full term infants (2% verses 6% on average, respectively).

The preterm baby's behaviour may not be as reinforcing as a full term baby's. One example is the age at which the baby begins to smile, a very rewarding experience for parents. The full term infant begins smiling at 5 weeks of age on average, the healthy preterm at 8 weeks on average and the ill preterm as late as 14 weeks of age, delaying reinforcement for parents' interactions (Goldberg, Brachenfield & DiVitto, cited in Holmes, Reich & Pasternak, 1984, p. 111). A second example is that the VLBW infant is reported as more passive and less intense in their interactions at 16 months of age than their full term peers, which may influence parent's behaviour towards their child over a long period, as more effort is needed to arouse their child and to get them to respond appropriately. Parents may gradually give up trying to stimulate their child as they receive little reinforcement (Barrera, Rosenbaum & Cunningham, 1987).

The preterm infant spends less time crying than their full term peers, crying on average 1% or 15 minutes per day compared to 12% (3 hours) for full term infants (Holmes, Nagy, Slaymaker, McNeal & Gardner, cited in Holmes, Reich & Pasternak, 1984, p. 111). The premature infant also spends less time awake, and only 9% of their awake time is spent crying, compared with 27% of waking time of full term infants. Although an infant who cries less is easier to care for and less frustrating for parents, the infant's cry is one of the first means of communication which demands attention from parents (MacArthur & Dezoete 1992). The premature infant who cries infrequently may not demand enough attention from their parents and hence may be easily ignored for longer periods of time, which may play a significant role in the disruption of development by eliciting less attention and stimulation from their parents (Holmes, Reich & Pasternak, 1984).

There are also differences in the quality of the premature infant's cries. For example, the preterm's cries are of a higher frequency than that of their full term peers and the abnormalities in the premature infant's cries may be more distressing to parents which is reflected in their stress levels (MacArthur & Dezoete, 1992). The detrimental affects of aversive cries is reflected in the lower performance on developmental assessments for children who were recorded as having more negatively perceived cries.

Feeding time provides opportunities for mothers to hold, make eye contact, talk and get to know their child. This may be an especially important time if the baby spends a lot of their time sleeping (Holmes, Nagy, Slaymaker, McNeal & Gardner cited in Holmes, Reich and Pasternak, 1984. p. 110). Mothers who prior to giving birth decided to breast feed may feel disappointment at not initially doing this, which may result in feelings of anger or inadequacy (Holmes, Reich & Pasternak, 1984). Once oral feeding is begun, breast feeding may still not be possible.

If their child's feeding is slower and not as productive as that of full term infants, feeding times may not be rewarding for the mother and, although this time is normally associated with bonding and getting to know their child, the mother may instead not enjoy the time and become frustrated because of their child's inability to feed (Stevenson, Roach, Vertbeve & Leavitt, 1990) especially if the child vomits after their feed (gastroensophageal reflux, Batshaw & Perret, 1992). Feeding times can be times of particular stress if there are concerns of growth, development and failure to thrive (Stevenson et al., 1990).

Overall, feeding problems may lead to slower than normal physical development. It may also affect the health of the child if their immune system can not protect them from illness. The failure to receive sufficient nutrients can lead to the re-admission into hospital of the child to receive nutrients and may be nutrients supplied by naso-gastric feeding until the child can absorb sufficient nutrients from their feeding. As a result parents may find feeding times particularly distressing and become anxious that their child is not feeding well. The hospital may not be as stimulating environment as home and the re-admission may lead to the disruption of parent-child interactions, especially as re-admissions frequently occur soon after the baby's discharge from the NICU. Their child's feeding problems may confirm parents' beliefs that they are not capable of looking after their baby and the medical staff do a much better job. This apparent undermining of the parent's confidence can impact on parent-child interactions and parents may become anxious that they are not providing every thing medical staff could for their child.

Behaviours of mothers of preterms towards their infant may differ from that of mothers of full term children. Mothers of preterms have been found to hold her child differently and for shorter periods of time (Amick, 1989). The baby is held further from the body and mothers do not reposition their child as often as mothers of full term infants. The preterm infant may not 'burped' as often as their full term peers, possibly because parents do not feel as comfortable holding their child and may feel they may hurt their child especially if the perception remains that their child is fragile (Goldberg, Brachenfield & DiVitto, 1980).

Long-Term Health Problems

Children born prematurely are at greater risk of having long term health problems that can be related back to their shorter gestation age, low birth weight and experiences in the Neonatal Intensive Care Unit (NICU). Infants learn a great deal of how the world operates in their first year and if they are retained in hospital for long periods there will be fewer opportunities for gaining age appropriate learning experiences. The hospital is also frequently not as stimulating environment as the home environment may be for the child to develop their cognitive abilities. The child's mobility in exploring their environment is also limited during periods of hospitalisation.

Zelkowitz, Papageorgiou and Allard (1994) recognised that hospital stays were infrequent and for short periods and suggested re-admission rates could be used as an indicator of periods of ill health, which in turn may prevent the child participating in age appropriate activities. It is also possible that parents of VLBW children susceptible to disease may minimise their child's contact with other children so not to expose them to disease, by keeping them at home rather than enrolling them in day care and pre-school activities.

Several studies have shown that a large proportion of VLBW children are re-hospitalised after discharge from the NICU. Re-admission rates ranged from 20-61%, compared to full term infants whose re-admission rate was 10-28% (Zelkowitz, Papageorgiou & Allard, 1994; Cunningham, McMillan & Gross, 1991; Bowman & Yu, 1989; Shankaran, Cohen, Linver & Zonia 1988) and 71% for ELBW children (Yu,

Manalapaz, Topin, Carse, Charlton & Gore, 1992). Zelkowitz, Papageorgiou and Allard (1994) found of the 47% of VLBW children re-admitted in their first year of life, 64% were re-hospitalised only once, while 34% were re-hospitalised two or more times.

Zelkowitz, Papageorgiou and Allard's (1994) study reported infections, such as bronchitis, pneumonia and gastro-enteritis, accounted for more than half (53%) of re-hospitalisations among VLBW children and the remainder of re-admissions were surgical procedures. Re-admission to hospital was associated with poorer performance on measures of cognitive development as well as less adequate social and academic competence as young as 6 years of age.

Early Education

Early experiences are important in the development of social, self help, cognitive and motor skills. Research has shown that children born prematurely believed to be at risk, who experience highly stimulating environments such as early educational intervention can experience cognitive 'catch up' with their full term peers (Weisglas-Kuperus, Baerts, Smrkovsky & Sauer, 1993). Children at lesser risk of developmental delay who experience less stimulating environments may experience developmental delay (Weisglas-Kuperus et al., 1993). Developmental outcomes of children involved in early educational interventions, such as the Infant Health and Development Program which provided the child with a stimulating environment, teaching them age appropriate skills and giving their parents social support, found the children did indeed experience cognitive 'catch up' with their full term peers, where children born prematurely not involved in the intervention program did not experience this (Ramey et al., 1992; Infant Health and Development Program, 1990).

Conclusions and Research Question

Children born prematurely have a higher incidence of disabilities and are at risk of developmental delay. Some studies have included children with intelligence scores within the population's average to examine whether prematurity alone places the premature infant at risk of developmental delay. These studies have reported a the

mean intelligence score of children born prematurely to be lower than full term children's and children born prematurely to have higher rates of repeating a school year than their full term peers.

The preterm birth and the infant's time in the neonatal intensive care unit has been proposed as somehow affecting the child's development. Parent's perceptions of themselves, their child, their behaviours towards their child not only during the child's time in the NICU but also after discharge and the infant's behaviour are believed may differ from that of parents of full term infants. The premature infant also may differ in their behaviours towards their parents and their environment. Both the infant and parent impact on the quality of parent-infant interactions.

There has been little follow-up of children born prematurely in New Zealand and whether the incidence of children born prematurely with a developmental delay are similar to those reported elsewhere. The current study was planned to look at the development of children with gestational ages of 32 weeks or less and/or with birth weights of 1500 grams or less admitted to Christchurch Women's Hospital during the period November 1992 to June 1993 and who had recorded selenium values. The children's development of fine motor, gross motor, communication, social and self help skills were assessed twice 3 months apart to determine the proportion of children, if any, indicating developmental delay at 17 and 20 months. All assessments were completed in the child's home in the presence of and with the assistance from the child's parent(s). The child's height and weight were to be measured at the first visit and information on the child's health, early intervention and any other significant happenings in the child's life since discharge from Christchurch Women's Hospital NICU, which may have affected developmental progress, was noted. Birth records were evaluated. The expected rate of development was that indicated by the authors of the Uniform Performance Assessment System (Haring, White, Edgar, Affleck, Hayden, Munson & Bendersky, 1981), the developmental assessment used.

Method

Participation and Informed Consent

The research-proposal and procedures for informed consent were approved by the University of Canterbury Human Ethics Committee and the Canterbury Area Health Board Ethics Committee. Applications with procedures and copies of approval letters are shown in Appendix 1.

The developmental assessment and developmental age of all the children were given to the child's paediatrician after both assessments were completed, who then could undertake a follow up of specific children who were developmentally delayed. Parents were referred to their paediatrician if they were concerned with their child's development.

Participants

Twenty-three children and their parents participated in this research. The criteria for the child's participation was

a) gestational age of 32 weeks or less, and/or

b) less than 1500 grams at birth and

c) admitted to the Neonatal Intensive Care Unit at Christchurch Women's Hospital between 1 November 1992 and 19 June 1993, and

d) had recorded selenium values at 28 days of age.

There were 47 children who met the above criteria (three children had since died, and 14 children lived some distance from Christchurch). Letters were sent to the parents of 30 children (Appendix 2). Consent forms for 20 of the 30 children were returned confirming voluntary participation of the family in the study. A second letter was sent to parents if no response was received. Three additional consent forms were returned. In all, twelve boys and 11 girls (77% of families contacted) participated in the current study. Two children could not be located, and five consent forms were not returned.

Of the 23 children, there were 6 sets of twins. The average chronological age of the children who participated was 17 months (range 14-20 months) at the first developmental assessment and 20.7 months (range 17-24 months) at the second developmental assessment. Respiratory distress syndrome was diagnosed in 19 children (13%), 16 of whom were treated with surfactant. Bronchopulmonary dysplasia was diagnosed in 7 children (30%), 8 (35%) children had abnormal cranial scans, ranging in severity from 1-3 and there were 7 cases of retinopathy of prematurity (30 %) ranging in severity from grade 1 (minimal changes in the retina) to 4 (blind) in one eye. Ten children were still on oxygen at 28 days of age (43%), 7 of whom were still on oxygen at 36 weeks post-conception age. Other medical characteristics of the infants during the peri-natal period are presented in Table 5.

Table 5.
Medical Characteristics of the 23 Study Children while in the NICU
(number, mean, standard deviation (S.D.) and range).

Factor	**Number of Children**	**Mean**	**S.D.**	**Range**
Gestational age (weeks)	23	29.2	2.3	24-32
Birth weight (grams)	23	1329.6	387.9	520-2030
Apgar score at 1 minute (minimum 1, maximum 10)	23	5.9	2.3	1-9
Apgar score at 5 minute (minimum 1, maximum 10)	23	8.2	1.9	2-10
Days ventilated	19	9.8	15.2	1-55
Days on oxygen	20	34.4	41.7	1-145
Days to Discharge	23	68.8	35.0	32-139
Plasma Selenium Value at 28 days of age	23	0.357	0.097	0.2-0.52
CRIB score (minimum 0, maximum 23)	23	4.0	4.0	0-13

Setting

All observations were completed in the child's home in the presence and with the assistance of one or both parents. Observations were completed in the home to improve the rate of participation, to reduce inconveniences incurred by families involved and to improve the quality of the assessment, as a more realistic assessment of current skills the child is capable of can be observed in the child's normal settings than in a new, unusual environment which may affect how relaxed the child was and therefore their co-operation.

Instrumentation

The Uniform Performance Assessment System (UPAS, Haring et al., 1981) is an assessment tool which assesses skills in four developmental areas

a) gross motor skills,

b) fine motor and pre-academic skills,

c) communication skills and

d) social and self-help skills.

In each category skills are arranged in developmental sequences by expected age and order of acquisition. The UPAS assessment is not a check list that parents or caregivers tick off skills they believe their children to have. Instead it involves the direct observation or testing of the skills by the researcher. Assessment can be categorised under one of three types:

1) observation of the skill occurring in a natural routine (as using a spoon during a meal)

2) test of the skill in a situation set up by the assessor or parent (as naming animals in picture cards)

3) parent report is used for a very few items when assessor is not able to observe (as toileting).

Skills expected to be achieved between 12-24 months and which are tested in UPAS are shown in Appendix 4. Skills hoped to be assessed during normal routine

(type 1), to be set up as a prompted assessment (type 2) or to be assessed through parent report (type 3) are indicated in Appendix 4.

The UPAS developmental assessment was completed twice, as close to three months as possible and no more than four months apart for each child. Two assessments were completed to give a more reliable indication of which children were and were not developmentally delayed and to estimate the rate of each individual's development.

The UPAS assessment (Haring et al., 1981) was chosen because it assesses natural skills in natural settings, that is in the home. The assessment is easily and quickly administered in the home environment and toys and objects used are found commonly in the home environment or are easily obtained for the assessment. The UPAS (Haring et al., 1981) skills cover a variety of developmental areas and within each category (gross motor, fine motor, communication and social and self help skills). Skills are ranked in the order they are expected to be gained and have an identified age range during which the skills are normally expected to be achieved.

Assessment techniques for individuals may be adjusted according to some abilities. For example, for a child with vision problems, prompted methods which may have required sight were substituted with toys with interesting noises.

The researcher was a fifth year Psychology student at the University of Canterbury who was experienced in using the UPAS assessment.

Procedure

Developmental Assessment

Once informed consent was received parents were contacted by telephone by the researcher and an informal meeting was arranged for the researcher to meet the parent and child. This initial meeting allowed time for any parent's queries to be answered and for the researcher to meet the child to assist in planning and preparing practical aspects of the assessment. Next, a time suitable for parents and when their child was usually alert and in good health was arranged for the UPAS assessment to be completed.

During the observations for the UPAS assessment, at least one parent was always present and assisted the researcher in encouraging the child to complete the skills required.

Feeding, fine motor, gross motor and language skills were observed and scored by the researcher during the child's normal daily routine, such as play time or a meal time, when ever possible. The child was prompted by her/his parents or the researcher to assess skills, including skills requiring manipulation of certain test objects (putting rings on a stick) or certain receptive language items (identify object by it's sound while hidden) or some expressive language items (imitate non-verbal sounds). As the child succeeded in passing each task, progressively more advanced skills were assessed, until the child had failed three skills in a row in each category (Appendix 4).

Each assessment period was planned to be no longer than one hour, so as not to tire the child. If at the end of the allocated time there were skills remaining which were untested, another time suitable for parents was arranged to complete the assessment.

At the completion of the developmental assessment, parents were sent a letter of thanks, notice of when they were to be contacted next and how to contact the researcher if they had any queries.

The same assessment procedure was followed for the second developmental assessment three months later. The letter sent at the completion of the second assessment included a list of the skills gained by the child between the two assessments and a graph depicting the gain of skills from the first assessment to the second assessment (Sample graph and letter are shown in Appendix 5).

Weight and Height Procedure

The child's weight and height were measured by the researcher before the first developmental assessment using metric bathroom scales and a metric tape measure.

Parent Interview

During the first meeting with the parent(s) and child, parents were asked for information that may be relevant to their child's current development level. This

information was considered important in analysing the child's development. The child's health status at the time of the assessments was also important because of its affect on the current developmental assessment. A copy of the interview is in Appendix 6.

Reliability

Two professional teachers, trained to use UPAS, served as reliability checkers. The developmental assessments of 8 children were observed by a second observer through direct observation at the same time and settings as the researcher. Items were scored independently.

Results

Twenty-three children were assessed twice each, three months apart. Both assessments were completed for 20 children over a period of three weeks three months apart. Several assessments were postponed because of illness or other factors, but no serious difficulties were encountered and no second assessment was completed more than four months after their first assessment.

The three later consents were received after completion of the first assessments. These parents and children were met and assessments were completed as soon as was convenient for the family.

Reliability

A total of 368 items were co-assessed over eight assessments (four each at time 1 and time 2). Reliability of each co-assessment was calculated by dividing the total number of agreements by the total number of skills co-assessed. This was multiplied by 100 to calculate the percentage of agreement. The mean inter-observer agreement was 93% (range 86-97 %).

Corrected Age in Calculations

In calculating the developmental age and rate of development of the child born prematurely, one of two measures can be used. One, the child's chronological age uncorrected for prematurity or two, the child's chronological age corrected for prematurity. In calculating corrected age for prematurity, the number of weeks the child is born prematurely is taken off the child's chronological age.

General consensus suggests age correction should not be used beyond 24 months of age (Batshaw and Perret, 1992). Since the children in this study were between 14 and 24 months of age at the times of the assessments, the results are calculated using chronological age corrected for prematurity.

Physical Development of the Children

Weight

The children's weight was converted to percentiles using corrected age at the date of measurement. The percentiles used were the same as used in the local paediatric department. Seventeen percent of the 23 children's weights were categorised below the third percentile and thirteen percent of the children had weight categorised above the 97th percentile (Table 6).

Height

The children's height at the first meeting was converted to percentiles using chronological age corrected for prematurity (Table 6). Twenty-six percent of children had heights categorised below the third percentile and thirteen percent of the children had heights categorised above the 50th percentile.

Table 6.

Percent of Children Within Each Weight and Height Percentile

(Calculations using corrected age).

Percentile	Weight	Height
<3	17	26
3-10	17	0
10-50	52	61
50-70	9	9
70-97	0	4
97<	4	0

Re-Hospitalisation

Seven children had not been re-hospitalised since their discharge from the NICU. Sixteen (70%) of the 23 children were re-hospitalised in the first year of their life. Of the 16 re-hospitalised, six were again hospitalised in their second year of life. The

children re-hospitalised spent between 1 and 31 days in total in hospital up to the date of their final UPAS assessment.

Continuing Health-Related Problems

Parents and medical records of 11 of the 23 children (48%) reported ongoing health related problems including asthma (6 children), failure to thrive (2 children), growth failure (1 child), chronic lung disease (1 child), heart murmur (1 child), susceptibility to upper respiratory tract infections (1 child) and hydrocephalus (abnormal increase in the amount of cerebrospinal fluid within the ventricles of the brain; 1 child).

Identifiable Disabilities

Medical records and parent interviews identified six children with the following disabilities: one child had cerebral palsy, spastic deplegia, mild truncal hypotonia (state of reduced tension in the muscle), palatal groove , mild hearing loss and strabismis and myopic vision. A second child had a slight hearing loss, had myopic vision in one eye and was blind in the other eye, a third child had truncal and limb hypotonia and had myopic vision. A fourth child had cerebral palsy, brain damage and one eye was affected by ROP, another child had a weaker side of their body as a result of IVH and finally one child had a genetic anomaly.

Developmental Level of the Children

The number of skills which were scored as meeting criterion levels at the assessment for each subsection of the UPAS were totalled. The raw score was converted to the developmental age in months (Haring et al., 1981). The developmental ages at the first assessment for each child are shown in Table 7.

Table 7.

Uncorrected Chronological Age and Chronological Age Corrected for Prematurity (months) of 23 Children and Their Fine Motor, Communication, Self Help and Gross Motor Developmental Ages (DA) in Months at the First Assessment.

CHILD	Chronological Age	Corrected Age	Fine Motor DA	Communication DA	Self-help DA	Gross Motor DA	Overall DA
A	20	16	9.5	10.5	6	4.2	6
B	19.5	17	26	24	25	14.5	21
C	18.5	16.5	9.5	12.5	14	9	11
D	18.5	16.5	13	12.5	14	9	11
E	19.5	16	11	14	14	3.7	7.5
F	18	14.5	25	16	24.5	17	19.5
G	18	14.5	22	16	24.5	17	19
H	17.5	15.5	27	14	25.5	17	20
I	17.5	15.5	27	12.5	25.5	16	19.5
J	17.5	13.5	17	16	8	9	12
K	16.5	14	28	24	26	20	25.5
L	16.5	14	26	12.5	14	15	16.5
M	16	13.5	25	12.5	14	15	16
N	15.5	13.5	27	18	19	11.5	17.5
O	15.5	13.5	27	18	24.5	16	20
P	15	12.5	25	12.5	24.5	17	18
Q	14	11	15	11.5	12	10	11.5
R	14	11	15	11.5	12	9	11
S	14	11	15	12.5	12	10	11.5
T	18	15.5	25	18	26	15	20
U	17	14.5	27	12.5	24.5	10	15.5
V	17	14.5	25	14	24.5	11.5	16
W	19.5	17	27	20	24.5	17.2	21.5
Mean	17.09	14.46	21.48	15.02	19.07	12.77	16.02
S.D.	1.82	1.89	1.55	3.78	6.72	4.38	4.94

All ages are in months.

DA = developmental age.

The difference between chronological age and developmental age can indicate developmental delay, however, determining developmental age is often not reliable for very young children. In the current study two developmental assessments were completed. Scores from the two assessments were used to calculate an average developmental rate (Figure 1; Odom, 1988). This was calculated for each child by

dividing the developmental age by the child's corrected age for prematurity at the time of the assessment (Figure 1).

Developmental Rate (DR) = $\frac{\text{Developmental age}}{\text{Corrected chronological age}}$

Average Developmental Rate = $\frac{\text{DR 1st assessment + DR 2nd assessment}}{2}$

Figure 1. Formula Used to Calculate Developmental Rate.

This product estimates the rate at which skills were acquired. A developmental rate of 1.0 would indicate that the child gains 'a month worth of skills' in a months time and in another example a child who gained 3 developmental months over a 6 month period would have a developmental rate of 0.5. The average of the developmental rates at time 1 and time 2 was calculated and shown in Table 8.

Children who were acquiring skills at slower than the average rate of 1.0 are generally considered to be either 'at risk' or delayed, depending on the extent of the difference from the expected average developmental rate.

A developmental rate between 0.70 or 0.75 to 0.85 (one standard deviation below the average) indicates children at risk of future learning disabilities. A developmental rate between 0.55 to 0.70 or 0.75 (2 to 3 standard deviations below the average) in one or more skills domains is considered a mild developmental delay in those particular areas and a child with a developmental rate of less than 0.50 to 0.55 (more than 3 standard deviations below the average) in one or more skill domain is considered to have a severe developmental delay in those skill areas (Batshaw & Perret, 1992). The standard deviations used were calculated elsewhere using a larger sample to estimate the average rate of development of the population (Batshaw & Perret, 1992).

Using chronological age corrected for prematurity in calculating the child's developmental rates, 18 children's developmental rates indicated no delay or indicated the child was at risk of future learning disabilities (developmental rate between 0.75 and 0.85) in any skill domain (Table 8).

Table 8.

Average Developmental Rates Using Age Corrected for Prematurity for 23 Children in Individual Domains and Overall.

	DEVELOPMENTAL RATE				
Child	**Fine Motor**	**Language**	**Self-Help & Social**	**Gross Motor**	**Overall**
A	0.67	0.68	0.54	0.28	0.43
B	1.44	1.38	1.39	0.89	1.25
C	0.68	0.97	0.79	0.51	0.72
D	0.97	0.91	0.79	0.51	0.73
E	0.67	1.06	0.91	0.22	0.47
F	1.65	1.31	1.60	1.13	1.40
G	1.49	1.31	1.60	1.13	1.39
H	1.61	1.11	1.51	1.07	1.33
I	1.61	1.04	1.51	1.04	1.29
J	1.42	1.23	0.71	0.63	0.93
K	1.81	1.68	1.78	1.33	1.70
L	1.76	1.19	1.30	1.03	1.30
M	1.69	1.20	1.08	1.14	1.28
N	1.85	1.33	1.44	0.97	1.38
O	1.85	1.33	1.66	1.18	1.48
P	1.87	1.27	1.88	1.31	1.53
Q	1.30	1.26	1.39	0.92	1.20
R	1.72	1.56	1.22	0.86	1.30
S	1.58	1.53	1.22	0.90	1.26
T	1.45	1.19	1.53	0.95	1.26
U	1.66	1.11	1.55	0.89	1.21
V	1.57	1.16	1.55	0.92	1.20
W	1.50	1.14	1.33	0.94	1.21
Mean	1.47	1.23	1.32	0.90	1.19
S.D.	0.37	0.22	0.35	0.29	0.32

Key

developmental rates between 0.85 and 0.75

developmental rates between 0.75 and 0.55

developmental rates less than 0.55

Average Developmental rate = 1.0.

Fine-motor and Pre-academic Development

Three of the 23 children (A, C and E) (13 %) had an average fine motor developmental rate of 0.75 or less indicating mild developmental delay (Table 8).

Communication Development

When the communication developmental rates were averaged between time 1 and time 2, one child's (A) developmental rate indicated a mild delay (Table 8). The remaining children were performing within the average rate.

Social & Self Help Development

One child (A) had an average self help and social developmental rate using corrected age in the calculations of 0.538 indicating a severe developmental delay (Table 8). A second child (J) had a corrected developmental rate which indicated a mild delay and two children had developmental rates categorised between the first and second standard deviation below the average (1.0) indicating the children were 'at risk' of future developmental delay in this skill domain (Table 8). The majority (84%) of children had acquired self help and social skills at an average rate.

Gross-Motor Development

Gross motor developmental rates were the lowest of all four skill domains (mean 0.90). Five (A, C, D, E and J) of the 23 children (22%) had gross motor developmental rate categorised at least two standard deviations below the mean (1.0) when the calculation used corrected age. The developmental rates of 4 children (17%) were categorised as severely delayed and one child's as mildly delayed (Table 8). Over three quarters (78%) of the children had developmental rates indicating the number of skills acquired was within the average range if they had been born at full term.

Overall Development

A total of four (17%) children (A, C, D and E) had an overall developmental rate categorised 2 or more standard deviations below the average (1.0) when calculations were based on corrected ages (Table 8). The developmental rates of two children (A and E) indicated severe delay and two (C and D) development rates were categorised between 2 and 3 standard deviations below the mean (1.0) indicating mild developmental delay (Table 8). The overall developmental rate did not reflect the

developmental rates of one child where a mild developmental delay was indicated in two of the domains.

The majority (78%) of children were developing within the average range, but 22% (5 children) were showing indications of mild to severe developmental delay in one or more developmental domains, using calculations based on corrected ages. One child's developmental rates indicated mild or severe developmental delay in all 4 skill domains and developmental delay was apparent in at least two of the four domains for four children (Table 8).

Factors Influencing Skill Development

Medical information collected during the peri-natal period of the children was reviewed. The data from the 5 children with developmental rates below two standard deviations from the average (below 0.75) in one or more domains was compared with the data of the other 18 children believed to be developing at a rate appropriate for their age. The means, standard deviations and the range of these medical data were calculated for each group (Table 9).

The five children with developmental rates indicating mild or severe delay in one or more developmental areas had on average the lowest at-birth ratings and NICU experiences, including 5 of the 7 shortest gestational ages (Table 9). The means for nine of the eleven factors showed significant differences using a student t-test. The children with delay had significantly lower gestational ages, birth weights and Apgar scores. They also had significantly more days ventilated days on oxygen, days in the NICU and days re-hospitalised. Factors with no significant difference included plasma selenium values at 28 days of age and the number of re-hospitalisations (Table 9). When the data is plotted (figures 2-10) the division of children with a developmental delay from those with developmental rates indicating no delay does not appear as obvious. The total number of days ventilated (figure 5), Apgar score at 5 minutes (figure 4), gestational age (figure 3), total days spent in the NICU (figure 9) and days on oxygen (figure 6) appeared to have a more obvious association with the child's developmental rate than birth weight (figure 2), plasma selenium value (figure 7), CRIB

rating (figure 8) and the number of days the child had spent in hospital since their initial discharge (figure 10).

Table 9.

Neonatal Factors of 5 Children with Developmental Rates indicating a Delay in One or More Skill Domains and 18 Children with Developmental Rates indicating no Developmental Delay.

	Children with a Developmental Delay	Children with an Average Development
Factor	**mean** *standard deviation* (range)	**mean** *standard deviation* (range)
Gestational Age (weeks)	**26.2**** *2.042* (24-28)	**30**** *1.534* (27-32)
Birth Weight (grams)	**930**** *343.88* (520-1130)	**1440.6**** *326.9* (940-2030)
Apgar score at 1 min (maximum score of 10, minimum score of 1)	**3.6**** *1.673* (1-5)	**6.5**** *2.065* (2-9)
Apgar score at 5 min (maximum score of 10, minimum score of 1)	**5.8*** *2.168* (2-7)	**8.8*** *1.098* (7-10)
Days Ventilated	**34*** *16.538* (16-55)	**3.1*** *3.894* (0-14)
Days on Oxygen	**94.2**** *130.671* (70-145)	**17.8**** *26.07* (0-91)
Plasma selenium value at 28 days of age	**.304** *.013* (.2-.44)	**.37** *.093* (.2-.52)
Days to Discharge from NICU	**115.4**** *23.881* (83-139)	**55.8**** *25.32* (28-110)
CRIB Score Maximum = 23 Optimum = 0	**8.8**** *2.168* (6-11)	**2.61**** *3.292* (0-13)
Total Times Re-hospitalised	**5.6** *4.722* (1-12)	**1.9** *2.055* (0-6)
Total Days Re-hospitalised	**15**** *12.629* (1-31)	**5.1**** *5.86* (0-22)

(t-test, **significant at p= 0.01; *significant at p= 0.05)

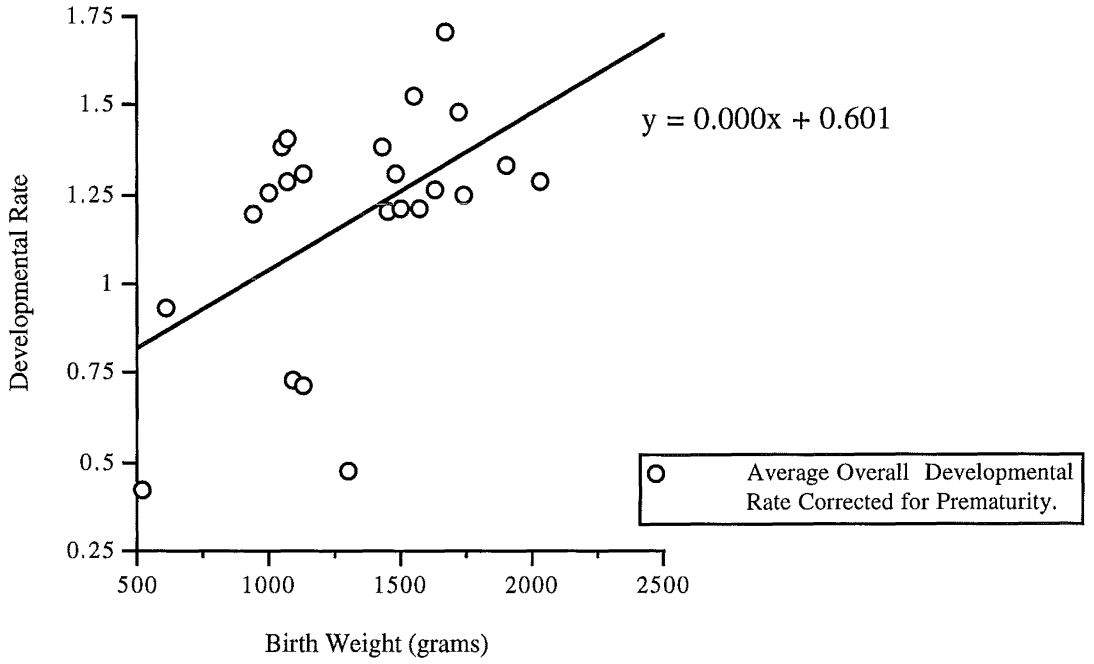

Figure 2. Birth Weight and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

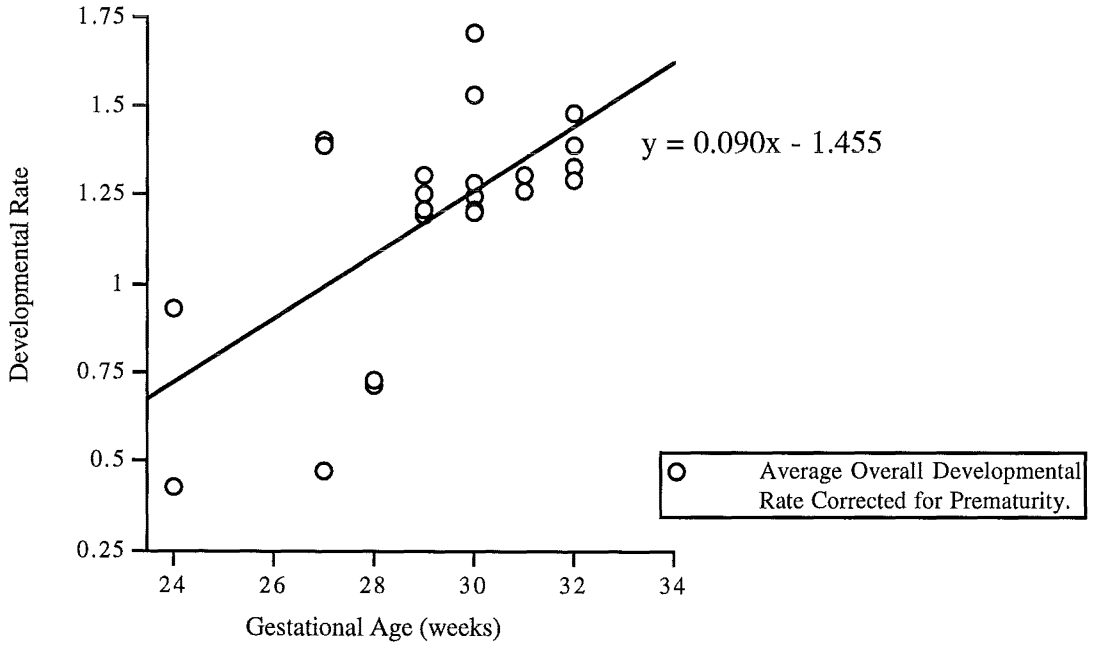

Figure 3. Gestational Age and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

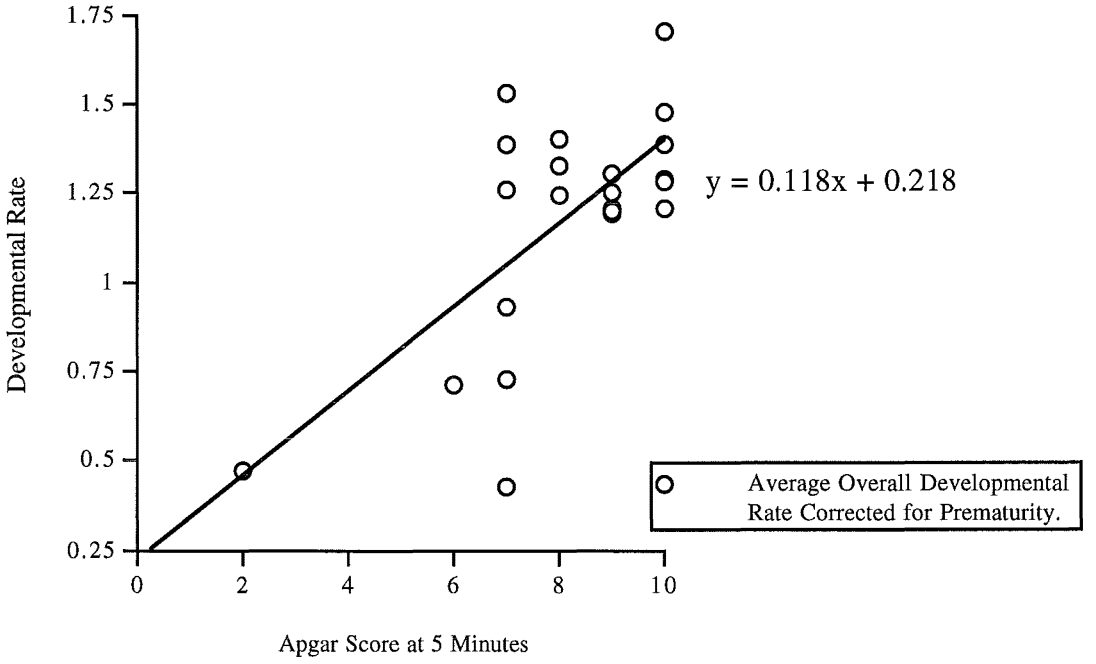

Figure 4. Apgar Score and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

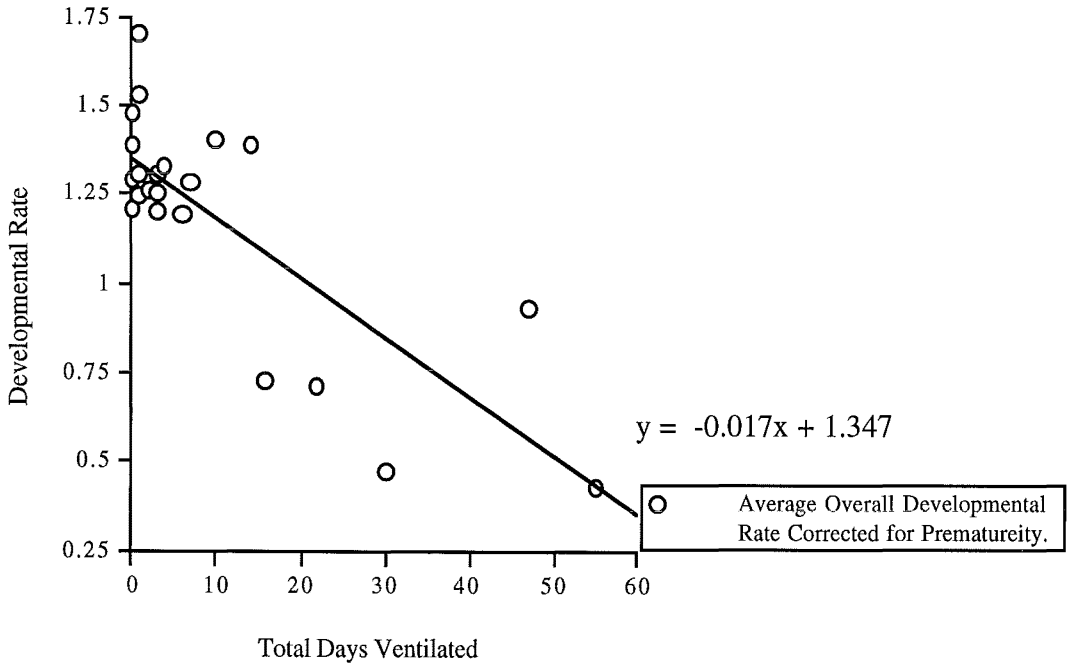

Figure 5. Total Days Ventilated and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

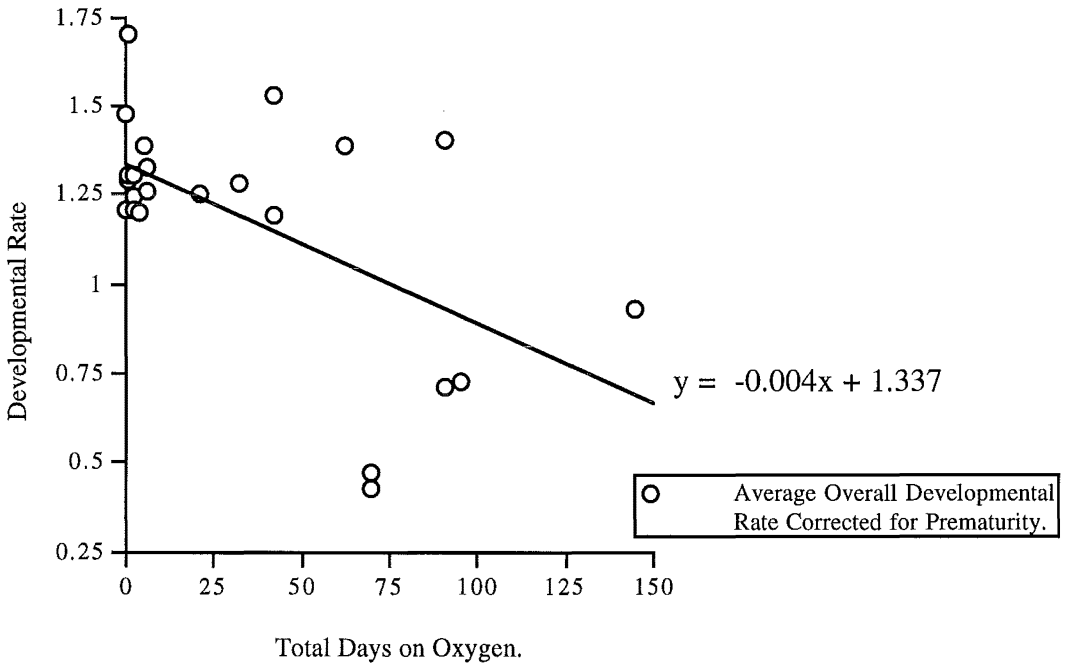

Figure 6. Total Days on Oxygen and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

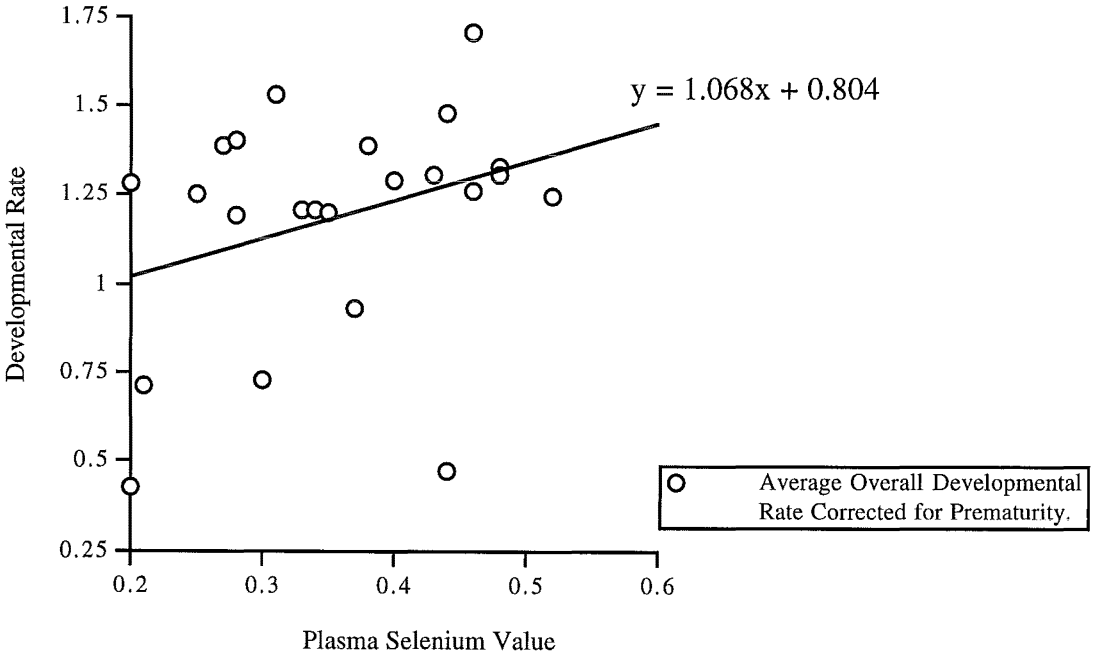

Figure 7. Plasma Selenium Value at 28 Days of Age and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

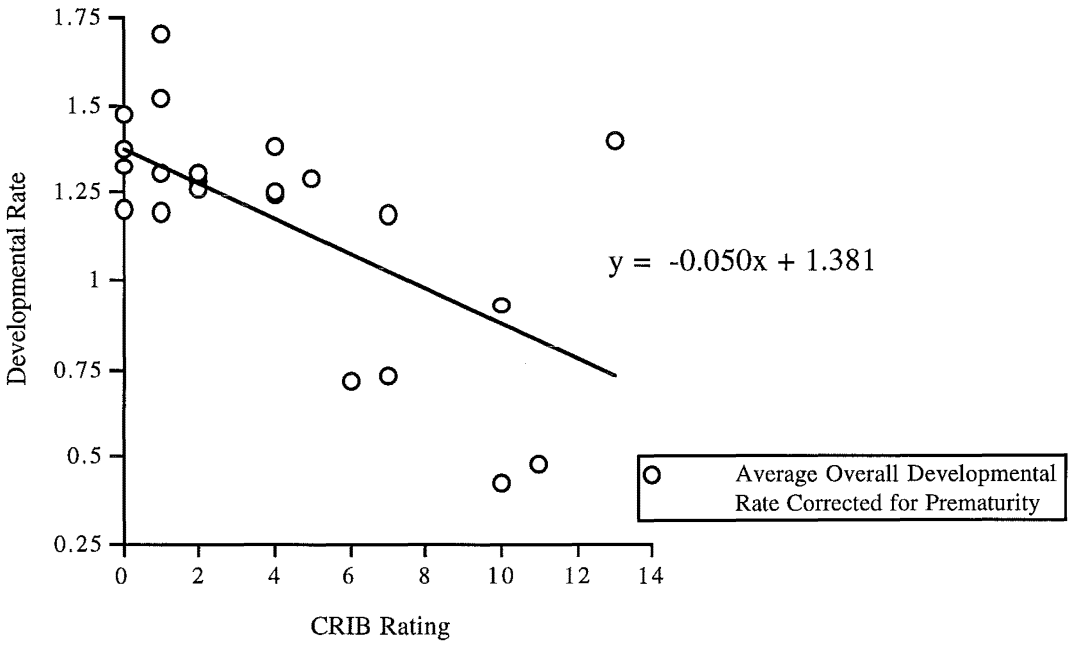

Figure 8. CRIB Rating and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

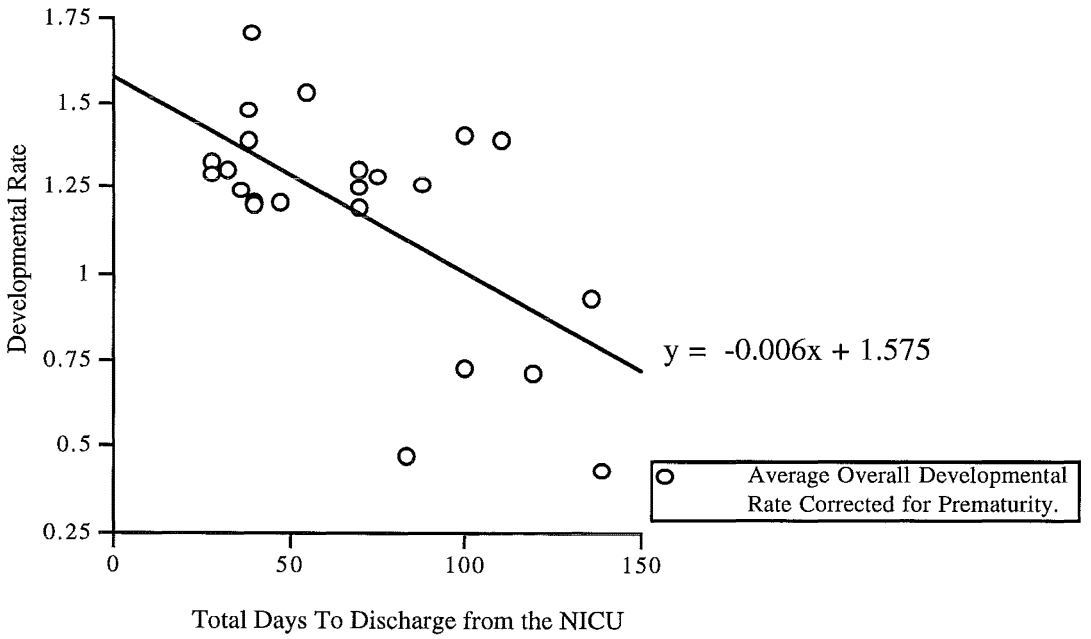

Figure 9. Total Days Spent in the NICU and Overall Developmental Rate in their Second Year of Life of 23 Children Born Prematurely.

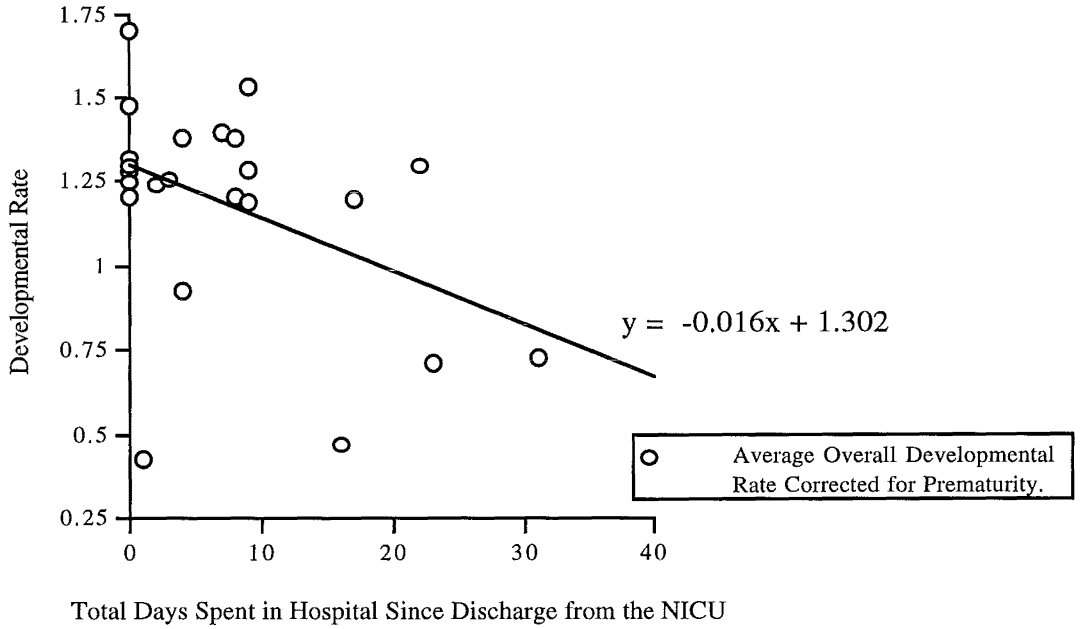

Figure 10. Total Days Spent in Hospital Since Initial Discharge and Overall Developmental Rate of 23 Children Born Prematurely.

In addition to these 11 factors, 3 other factors were examined. Four (80%) of the five children with a developmental delay and three (44%) of the children without a developmental delay had bronchopulmonary dysplasia in the peri-natal period. Three (60%) of the children with developmental rates indicating delay had ROP diagnosed (grades 3, 3 and 4). Three of four children responded favourable to cryotherapy and ROP resulted in blindness in one eye and loss of vision in the other eye for the final child. Two (11%) of the children with average developmental rates were diagnosed with ROP (grade 2 in both cases) which spontaneously recovered within the peri-natal period. Abnormal cranial scans were reported in three (60%) of the children with developmental rates indicating delay and two (11%) of the children with developmental rates within the average range. The haemorrhage:ventricle grades of the 3 children with a developmental delay were 0:1, 3:1 and 3:2 and the other 2 children with abnormal cranial scans had grade I haemorrhage scores.

Four (80%) of the children with developmental rates categorised as delayed had 2 or more identified disabilities (2 with cerebral palsy, 2 with mild hearing loss, 4 with vision impairment, 1 child had a cleft palate and 2 cases of hypotonia) and four (80%) had on-going health problems since discharge from the NICU (there was one case each of failure to thrive, chronic lung disease, susceptibility to upper respiratory tract infections, growth failure and hydrocephalus). Three (60%) of the children with a developmental delay had been re-hospitalised three or more times and had three of the four highest total days spent in hospital since discharge from the NICU. Asthma was the only on-going health concern noted in the group of children with no apparent developmental delay where 6 cases were reported.

For one child with a mild developmental delay, body weight was categorised as below the third percentile and two children had weights for their age corrected for prematurity categorised between the third and tenth percentile. The heights of two children with apparent developmental delay were categorised below the third percentile for their corrected at the time of measurement.

Eleven children in total received early educational intervention. Five of the six sets of twins were enrolled in early intervention and all five children with a suspected developmental delay had been enrolled in early intervention since discharge from the NICU and were also receiving physiotherapy.

Discussion

Development

Premature infants are at risk of developmental delay. Severe developmental delays[1] should become evident by 12 months of age, milder degrees of developmental delay[2] by 36 months of age and learning disabilities[3] during the formal schooling years (Liberty, 1993).

The majority (78%) of children at 14 to 24 months using the child's age corrected for prematurity in the current study were developing within one standard deviation of the average (1.0) in all four skill domains (fine motor, communication, self-help and social and gross motor). The other children (22%) had a developmental delay in one or more skill domains. A severe developmental delay in at least one skill domain was apparent in 17% of the children and a mild delay in 4% of the children. Severe developmental delay was apparent only in the gross motor development. Developmental rates in skill domains other than gross motor revealed cases of mild delays (13% fine motor, 4% communication and 17% in self help and social skills). Children with a developmental delay in one domain had a delay in at least one other skill area, suggesting development of skills is inter-related but delay in one domain does not necessarily confirm the same developmental rate in all domains. The overall scores in the current study were not an accurate reflection of the child's development as a whole; rather it averaged the scores of the four skill domains. The overall developmental rate of one child failed to recognise an apparent mild delay in gross motor and self help and social development. These delays were detected only when examining the individual developmental rates. Because of the lack of sensitivity of the overall developmental rate, skill areas should be calculated and examined separately.

It is difficult to interpret and compare the prevalence of delay with previous studies as the type of population studied, the instrumentation, and the definition of delay differed. Many studies reported the mean developmental quotient of the children born prematurely rather than reporting the number of children developing at a rate

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[1] developmental rates less than 0.55, below three standard deviations from the average.
[2] developmental rates between 0.55-0.75, between two and three standard deviations below the average.
[3] developmental rates between 0.75-0.85, between one and two standard deviations below the average.

appropriate for their age and the proportion of children with a developmental delay (Censullo, 1994; Rickards et al., 1993). Developmental quotient (mean 100) is the same as the developmental rate (mean 1.0) used in the current study. The incidence of overall developmental rates indicating developmental delay in the current study are compared with studies which investigated the developmental outcomes at 36 months of age of children born prematurely (Table 10). In all calculations the children's age corrected for prematurity was used.

Table 10.

Developmental Outcome of Children Born Prematurely at 36 Months of Age and the Development of Children in the Current Study.

	Developmental Rate (%)		
Birth Weight	**< 70**	**70-85**	**85<**
<1500 grams			
Infant Health & Developmental Program (1990)	28.7	34.6	36.7
Smith, Ulvand & Lindemann (1994)	21.1		78.9[4]
Croy (1995)	13	13	74
<2000 grams			
Infant Health & Developmental Program (1990)	22.9	30.7	46.4
Elliman, Bryan & Elliman (1986)	3.8	1.6[5]	94.6[4]
Croy (1995)	9	9	82
<2500 grams			
Infant Health & Developmental Program (1990)	21.2	32.8	46.0
Liaw & Brookes-Gunn (1994)	32.9[6]	20.7[7]	46.4
Croy (1995)	9	9	83

[4] developmental rate 80<
[5] developmental rate 70-79
[6] developmental rate <75
[7] developmental rate 75-85

Correcting Age for Prematurity

Although age corrected for prematurity was used in the calculations, the majority of children in the current study were acquiring skills within the average range when uncorrected age was used to calculate developmental rate (Appendix 7). Using uncorrected age in calculating developmental rates, only one child's overall developmental rate was re-categorised from indicating no delay to mild developmental delay. However, in individual skill domains several developmental rates were re-classified. The gross motor domain had the most adjustments with six developmental rates re-categorised. Two children who had corrected gross motor scores indicating no delay, were re-categorised as 'at risk' when no age correction was used in the calculations of the developmental rate. Three scores previously categorised as not delayed were re-categorised as mildly delayed and one gross motor developmental rate previously indicating mild delay, was re-categorised as severely delayed. The five children already identified as having a developmental delay remained the only children with a delay when calculations used uncorrected age in the fine motor, communication and self-help and social scores. A number of developmental rates were re-classified a category down.

It is possible that calculations of developmental rates no longer need to use age corrections for prematurity after 12 months of age and age correction should definitely be stopped after 24 months of age.

Catch up

'Catch up' of development may be achieved between 12 and 24 months of age and possibly by 18 months of age (Batshaw & Perret, 1992). It is not known whether 'catch up' is achieved in all skill areas concurrently or different developmental domains require different periods of time. Three children who at the time of the first assessment were 14 months of age (uncorrected age) had developmental rates indicating mild gross motor delay which subsequently disappeared when the corrected developmental rate was used. Three months later (17 months of age) the same three children's uncorrected gross motor score indicated no developmental delay (Appendix 7). 'Catch up' appeared

to be achieved before the first developmental assessment for fine motor, communication and social and self help skills as the majority (78%) of children's developmental rates calculated using uncorrected age, indicated no developmental delay at the first or second assessment (Appendix 7).

Once the 'catch up' phenomena is achieved developmental rates no longer need to be calculated using age corrected for prematurity. Developmental delay may go undetected if corrected developmental rate is used beyond an age once catch up is achieved or could have been achieved (Batshaw & Perret, 1992).

Physical Growth

The children in this study continued to be shorter and lighter at 14-20 months of age than the average heights and weights of children their age. This remained the case when calculations used the child's age corrected for prematurity. Eighty seven percent of the children's weight and height allowing for their premature birth remained below the 50th percentile, 35% of whom had weights categorised below the 10th percentile and 26% had heights categorised below the 10th percentile. Only 17% of the children had birth weights categorised as small for gestational age (below the 10th percentile). It appears that 'catch up' does not occur in the physical development of the children. This is consistent with current research (Zelkowitz; Papageorgiou & Allard, 1994; Elliman, Bryan & Elliman, 1986; Crombie & Darlow, 1986).

Disabilities

The incidence of cerebral palsy in this study was 9% and vision impairment was 17%. This, though higher than many current studies, falls within the range of reported incidence. Previous studies reported the incidence of cerebral palsy between 5-9% for children with birth weights less than 2000 grams and 1500 grams (Elliman, Bryan and Elliman, 1986; Liberty, 1993), and vision impairment between 12-18% (Zelkowitz, Papageorgiou & Allard, 1994; Victorian Infant Collaborative Study Group, 1991). The incidence of hearing impairment in the current study was 9%. This is higher than 3-6% reported in previous studies (Victorian Infant Collaborative Study Group, 1991; Hunt,

Tooley & Harvin, 1982). The children with cerebral palsy had severe gross motor developmental delay, as did the child with severe vision impairment. These children also had delays, although not severe, in other skill areas. One child with cerebral palsy had a developmental delay in all four domains (fine motor, communication, self help and social and gross motor). The presence of a palatal groove which results from the inside of the mouth moulding to the shapes of tubes in the mouth of one child is suggested may cause expressive language delays (Thorp & Raver, 1991). The expressive language of the child with a palatal groove, though delayed, did not differ from their receptive language development. The incidence of children with disabilities in New Zealand appears similar to that reported elsewhere and the presence of a disability appears to affect development during the child's early years.

ROP in one case resulted in blindness in one eye and vision impairment in the other. This can affect gross motor development if the child is not confident of their surrounds and fine motor skills may be affected because they cannot see the tasks placed before them and it makes learning by imitation difficult.

Medical Factors

The children with a developmental delay were, on average lighter at birth, had shorter gestation periods, lower Apgar scores, spent more days on ventilation, and oxygen and spent longer in the NICU than the children without a developmental delay. The medical course of the children with a developmental delay also appeared to be of greater concern with a higher incidence of bronchopulmonary dysplasia, retinopathy of prematurity and abnormal cranial scans and of more severe stages reported in children who showed delay in this study. The more severe the medical factors during the child's stay in the NICU the more likely the child will remain in hospital for a longer period of time. This can place the family under stress as their child's future may remain uncertain. Parent's taking care of their child is also delayed possibly decreasing their confidence in themselves as capable of looking after such a sick child. Physical contact and beginning a daily routine with their child is also delayed if the infant remains sick. The more severe the medical problems and the longer the infant remains in the NICU,

the greater the chances parent's perceptions of their infant as a fragile may be reinforced and this 'cognitive set' of their infant to possibly continue beyond the NICU even if it is no longer relevant to the child (Amick, 1989).

Selenium Status

Selenium status at 28 days of age was suggested to be associated to medical prognosis within the NICU. Infants with low plasma selenium status were more likely to be diagnosed with ROP, IVH or BPD. It was suggested this was because selenium protects the infant against oxygen free-radicals which leads to tissue damage and in the premature infant ROP, IVH and BPD, three possible outcomes of oxygen free-radical damage are of particular concern. However, there appeared little association between the child's plasma selenium status at 28 days of age and their developmental progress in their second year of life. The mean plasma selenium value at 28 days of age of children with a developmental delay was lower than that of children with no delay, however there was not significant difference. It is difficult to interpret this result with great confidence because of the small sample size in particular the small number of children with a developmental delay. Secondly it is not known by the researcher the selenium status of those children within the cohort who met the set criteria but who had died since discharge or those who did not agree to participate in the study.

CRIB Score

The CRIB score collated in the NICU for each child, ranged from 0 to 13 (International Neonatal Network, 1993). The mean CRIB score of children with a developmental delay was significantly higher (range 6-11), however the child with the highest CRIB score had no apparent developmental delay as did a child who had a CRIB score rated as 7 (within the range of CRIB ratings typically scored by children with a developmental delay). The CRIB score does not appear to be a sensitive predictor of development within the child's second year of life.

Chronic Illness & Re-Hospitalisation

Since discharge from the NICU all the children with a developmental delay had been re-admitted into hospital in their first year of life and 40% of children with a delay and 6% of children with no delay were re-hospitalised in their second year of life. Forty percent of the children with a developmental delay accounted for the most frequent re-hospitalisations and highest total days spent in hospital since initial discharge. Sixty percent of the children with a developmental delay and 28% of children without a developmental delay had been re-hospitalised three or more times. Zelkowitz, Papageorgiou and Allard (1994) proposed that the number of times the child was re-hospitalised and the total days they spent in hospital could be used as an indication for chronic and serious illness. Chronic illness rather than re-hospitalisation per se, may affect the rate of development. Recurring sickness may lead parents to attempt to minimise their child's exposure to future illness by restricting their child's participation in age appropriate activities and experiences. Frequent bouts of illness may result in the child's withdrawal from activities until recovery, all of which can have an adverse affect on the development of the child born prematurely. The withdrawal from normal experiences may lead to developmental delay as children learn a lot about the world in their early years through the environments they encounter, their experiences and from people they meet (Robinson & Jackson, 1991). Disruption of learning experiences may cause a snowball effect. The later early skills are learnt, the longer following skills will take. For example, if a young child takes longer to learn to stand independently, the older they will be before walking and using stairs independently. Some skills are especially important such as walking and making babbling sounds as they are a prerequisite of other skills. Early recognition of the failure of prerequisite skills can lead to early educational intervention to assist in the 'catch up' of such skills and the prevention of further developmental delay.

Associations with Developmental Delay

It is acknowledged that children born prematurely are at greater risk of developmental delay. This delay has been associated with birth factors and the child's

medical course during their stay in the NICU. Although the mean values for medical factors (days on oxygen, etc.) experienced by children with a delay and without a delay differ significantly in this study, when examining individual medical courses and data ranges, considerable cross over occurs. One example is birth weight. The children with the two lightest birth weights in this study have a developmental delay yet the children with the next five lightest birth weights do not have an apparent delay. The remaining children with a developmental delay have birth weights indistinguishable from the other children with no delay. This cross over of data occurs in ten of the eleven medical factors looked at, the exception is the number of days ventilated, however, the significance of the difference between the two groups is decreased because of the large standard deviation. If birth weight was to be used as a predictor of development in this study, a cut-off point of at least 1130 grams would be needed. Maintaining this cut-off would include five children without apparent delay, however a cut off point any lower would exclude children with a developmental delay. One factor alone can not accurately predict the future development of children born prematurely.

It is not known why some children with similar medical courses develop within the average rate for their age, while others have an apparent developmental delay.

Prediction of Developmental Delay

It is important in providing and allocating limited early intervention resources, to be able to identify those infants and children who are at most risk of developmental delay. The accurate and efficient allocation of resources early in life aims to prevent and minimise delays at a later stage. Peri-natal and medical factors, such as birth weight or gestational age, viewed separately do not appear to be highly accurate in assessing which children are at risk of developmental delay at the time of NICU discharge. Because of this risk indices combining various neonatal and medical factors have been developed to identify premature infants at risk of developmental delay. The risk formulations attempt to predict which of the many different aspects of prematurity that can occur during the neonatal period may place the premature infant at risk of developmental delay. Some of these are intraventricular haemorrhage, days ventilated

or on oxygen. Risk indices may be inventories of the individual infant's medical course, that is a list of factors which is answered 'yes, this did occur' or 'no, this did not occur' and summed together. The more factors present, indicate the child at higher risk of developmental delay. Other indices attempt to extrapolate particular factors presumed to place the child at risk, and others may place more emphasis on various factors than others.

Multi-factor risk assessment

The multi factor risk assessment identifies a variety of the infant's characteristics, such as weight and gestation age, and neonatal medical complications. Any one factor may indicate the child is at greater risk of developmental delay.

An example of a multi factor risk assessment is the Neonatal Medical Index (NMI, Korner, Kraemer, Spiker, Scott, Constaantinou and Dimiceu, 1993). The NMI is a classification system of various neonatal characteristics and medical complications which summarises the infant's medical course in the NICU and gives the infant a summary score from I, infant free of significant past medical problems, through to V, characterising infants with the most serious complications Infants with higher NMI ratings are perceived to be at greater risk of subsequent cognitive and motor delay. Among the characteristics and medical complications noted are birth weight, respiratory distress syndrome, days on ventilation, intraventricular haemorrhage, apnoea, bradycardia and seizures (Korner et al., 1993; Appendix 3).

Weighted-risk assessment

In the weighted risk assessment, many of the same medical factors and infant characteristics (such as respiratory distress syndrome, days on ventilation) are noted, though, in the weighted risk assessments, some factors are considered to have more impact on whether the infant is at risk of future developmental delay. For example, IVH grade IV may place the infant at greater risk of developmental delay than having a birth weight of more than 1500 grams. The IVH of grade IV is therefore given a

heavier weighting than birth weight. Once again the score is summed to come to a risk rating.

An example of weighted risk assessment is the Neurobiologic Risk Score (NBRS, Brazey, Goldstein, Oehler, Gustafson & Thompson, 1993). Seven medical complications that can occur during the preterm infant's neonatal time are graded. If the factor is not present it receives a score of zero, more extreme cases score a maximum of 4 points and there are intermediate scores between the two extremities. Once all added together, an infant with a score of 4 or less is considered to be at low risk of motor and mental developmental delay, children with a score from 5-7, are considered at intermediate risk of future delays and a combined score of 8 or more indicates children believed at high risk of developmental delay (Brazey et al., 1993).

Prediction of development for any one infant is difficult to make because of differences in the preterm's specific medical course and subsequent environments. It is currently unknown whether plasma selenium levels can be used as a risk factor of developmental delay (Batshaw & Perret, 1992).

Neonatal Medical Index

The NMI (Korner et al., 1993, Appendix 3) was applied to available NICU records of the children in this study. Korner and colleagues (1993) reported the NMI was predictive of later development and was especially sensitive in the prediction of the development at 3 years of age of children with birth weights 1500 grams or less and mildly predictive of motor development at 12-24 months in heavier premature infants. Children in this study, who at NICU discharge would have received a rating of IV or V, scores indicating a more complicated NICU medical course, were the children with apparent developmental delay between 1 and 2 years of age. All the children with no apparent developmental delay had medical records which received a NMI rating of I, II or III (low risk of developmental delay to some risk of developmental delay). There was no over lap of ratings, that is no child with a developmental delay received a rating lower than IV and no child without apparent delay received a NMI rating greater than

III. The NMI ratings appeared to accurately predict from NICU medical records the children who had a developmental delay in their second year of life.

Early Educational Intervention

The development of the child is not set at birth but is instead modifiable by their experiences and environments they encounter (or do not encounter) throughout their life (Clarke & Clarke, 1992). A learning delay at one stage of the child's life does not necessarily mean the child will always have a delay. With the appropriate encouragement and learning experiences, the learning delay may be reversed or minimised (Clarke & Clarke, 1992). Early educational intervention is reported to have long term positive effects on the development of children born prematurely. An accurate method of determining which children are most at risk of developmental delay at the time of discharge from the NICU would result in children most in need of early educational intervention receiving it.

Approximately half (48 %) of the study children were enrolled in an early education intervention. Five of the six sets of twins received early intervention as did all the children with a developmental delay. The child with the highest CRIB rating reflecting NICU medical course, had no apparent developmental delay and had received early educational intervention. Half of the six children who received a NMI rating of 3, were receiving early educational intervention. All 6 children had development scores indicating no developmental delay.

Although the current study did not examine the effects of early educational intervention on development, many studies have supported the effectiveness of early educational intervention on improving developmental outcomes of children born prematurely. Intervention begun within the first three years of life has been reported to have the most powerful and lasting impact in preventing or minimising developmental delay and failure at school (Slavin, Karweit & Wasik, 1993). Early educational intervention is more effective than later intervention such as remedial classes once the child has entered school (Slavin, Karweit & Wasik, 1993).

Achenbach and colleagues (1988, 1990, 1993) followed the development of children born prematurely, some of whom were enrolled in the Vermont Intervention Program. The development of children enrolled in early educational intervention achieved 'catch up' with full term children, and began to diverge significantly from low birth weight children not enrolled in the intervention, at 3 years of age. This difference continued through to age 9 when intervention children scored higher on cognitive and achievement test scores than low birth weight children not enrolled in intervention.

A second follow up study supporting early educational intervention is the Infant Health Development Program (IHDP, 1990). The program consisted of home visits in the child's first two years of life, in which time developmental and health information was provided and children attended a development centre from 12 to 36 months of age. At age 36 months children involved in intervention had significantly higher IQ (intelligence quotient) scores than children born prematurely who were not involved in early educational intervention. The delay of development in children at biological risk appears to be preventable if the child is in a stimulating environment (Weisglas-Kuperus et al., 1993). Early educational interventions aim to enhance the child's environment and experiences stimulating the child's cognitive, language and motor development in the expectation of preventing developmental delay. The opposite of this is also true, a child not at high risk of developmental delay in a non stimulating environment may experience developmental delay (Weisglas-Kuperus et al., 1993). The prevention of developmental delay would lead greater academic success in formal education and a reduction in the need of remedial classes and children repeating a school year (Achenbach et al., 1990, 1993; Rauh et al., 1988).

Limitations

The findings of the current study need to be treated with caution. The sample size was small and a small time span was used. Bias may have occurred because of the seven non-participants, although an attempt to minimise failure of responses was made by sending a second letter to each of these parents.

Another possible limitation may have resulted from the accuracy of which young children's development can be assessed. Measures assessing the development of young children need to have a large age range in which it is acceptable for skill acquisition. The UPAS assessment (Haring et al., 1981) for example gives an indication of the average age children learn to walk as between 12 and 24 months of age. The total mean skill acquisition rate used is 1.0 and developmental rates 0.15 points on either side are accepted as average. This margin usually allows for children learning skills at the older end of the age range. Nevertheless when skills such as standing independently are pre-requisites for many other skills, in this case walking up and down inclines and stairs, crouching and running, the late development of standing alone will reflect in the non-achievement of following skills. Developmental rates here may give the impression that the child has a delay although this is not necessarily so. This may have been the case in the current study. Four children were not standing independently at the first assessment and their gross motor developmental rate uncorrected for prematurity indicated a mild developmental delay, yet at the second visit the children were standing independently and walking and no developmental delay was evident.

Repeated measures were used to determine the child's developmental age and the two developmental assessments were averaged because the calculated developmental rate from the second assessment was higher than from the first assessment. This may have resulted from the researcher knowing the child at the second assessment and having a better knowledge of what prompting work for the child. Paralleling this the child and parents knew the researcher and may have felt more at ease during the assessment. Parents also knew more of what to expect during the assessment and were more relaxed in assisting the researcher.

Parents' perceptions of the examiner's expectations of their child's development may have contributed to the intentional teaching their child skills they did not pass at the first assessment. Casual statements made by parents at the second assessment suggest they may have been concerned at their child not passing all the skills presented at the first visit. This was despite the fact that prior to each assessment it was explained that part of the procedure was for the child to fail three items before the assessment was

completed. This was to ensure the top limit of the child's abilities were tested, otherwise an under-estimation of skills may have occurred.

Developmental assessments test a limited number of skills, some of which may have been encountered previously by some children and not by others, which are then used for an estimation of overall development. The UPAS (Haring et al., 1981) assessed skills grouped into four categories, fine motor, communication, self help and social and gross motor. Although parents may have recognised many other skills their child had learnt between the two assessments, only skills in the UPAS assessment were used in the calculation of the child's developmental age to be consistent across all the children.

Conclusions and Future Research

In New Zealand children born prematurely do appear to be at risk of developmental delay and the incidence of children born prematurely with a developmental delay in this study appears similar to that reported elsewhere. Because of the long term effects premature birth and the medical factors premature infants are at risk of, can have on development, and increased rates of disability, preventing premature birth needs to be a priority. Educating expectant mothers, particularly those at increased risk of giving birth prematurely (e.g. teenagers) of preventive measures such as a healthy diet, regular check ups and no smoking is one method of achieving this.

Premature infants who are at risk of developmental delays need to be identified as early as possible so they can be referred to early educational intervention. The Neonatal Medical Index (NMI) is an easy predictive index to administer and the information needed is already collected and readily available at the infant's discharge (Korner et al., 1993). Further research is needed on the accuracy of developmental risk indices for the premature infant and to preventing the factors that place the premature infant at risk of developmental delay. The follow-up of the development of all children born prematurely to their school years including those children without obvious developmental delays and disabilities, is needed. Mild developmental delays may not

be recognised until 36 months of age and learning disabilities until schooling is begun. What impact medical factors, neonatal care and the child's early experiences have on development needs examination. Although selenium was found not to be a predictor in the current study because of the small sample size and no previous research examining selenium status and developmental progress some further research needs to go into this area.

When assessing the development of children born prematurely the separate skill domains need to be examined individually (e.g. fine motor, communication, self help and social and gross motor) as an overall developmental score does not necessarily reflect the child's whole development.

Early educational intervention as simple as informing parents of what to expect from their premature infant and how to respond effectively to their infant's demands has had lasting effects on the children's development in previous research. Early educational intervention does not need to be expensive to appear effective.

The majority of children born prematurely are developing at a similar rate as their full term peers, however, this population is at higher risk of developmental delays even as young as 14-24 months of age. Care is needed to follow the development of children born prematurely to ensure all children needing early educational intervention are receiving it so to prevent and minimise future delays such as learning disabilities which are recognised only once the child has begun school.

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APPENDIX 1

Applications to Canterbury Area Health Board Ethics Committee

&

The University of Canterbury Human Ethics Committee

With

Letters of Approval

CANTERBURY AREA HEALTH BOARD ETHICS COMMITTEE APPLICATION

HUMAN RESEARCH PROJECT

THE PROJECT

1. Title of project: Assessment of the development of premature infants.
2. Investigators: Carol Croy - Enroled as Masters of Arts student (Psychology Department) at University of Canterbury.
3. Name, address and phone number of principle Investigator:
   Carol Croy
   (address)
   (telephone number)
4. What experience does the researcher have in this type of research?
   Previous experience in developmental assessment of children.
5. Research Supervisors if not included above:
   Dr. Kathleen Liberty: Education Department, University of Canterbury.
   Neville Blampied: Psychology Department, University of Canterbury.
   Dr. Brian Darlow: Christchurch School of Medicine
6. Is this a multicentre trial? If so where is the Principle Investigator based? No
7. Is approval from other Ethics Committees being sought? If so, please supply details. Yes
   University of Canterbury Human Ethics Committee.
8. Is the project
   - a continuation of an existing study?
   - a new project? A new project
9. What is the project's -commencement date?
   1st May, 1994
   -estimated completion date?
   28th February, 1995.
10. The EC requires at least an annual report. What will be the reporting date for this project? 1st March, 1995.
11. What is the object of the project? Explain in appropriate language for a lay person.

The purpose of the current study is to determine if premature infants born between November 1992 and May 1993, with birth weighed less than 1500 grams and gestation age less than 32 weeks, who were admitted to the Christchurch Women's Hospital

Neonatal Intensive Care Unit are developmentally delayed at 18 months of age by assessing their skill levels.

Secondly, the data would be analysed to determine if a statistical relationship between developmental age at 18 months and selenium level at one month of age exists.

12. 12.1 How if at all will this project benefit participating subjects?

Parents will be involved in assessing their child's developmental skills and will receive feedback from the observations of their child's skills and progress.

12.2 How if at all will this project benefit the researcher?

Researcher will learn valuable skills in the areas of:

-literature search and reviewing relevant past research,

-communication skills with parents,

-interaction with children,

-developmental assessment of children with possible developmental disabilities,

-data analysis.

12.3 How if at all will this project be used to formulate policy?

No plans

13. Is this project therapeutic or non-therapeutic research?

(see declaration of Helinski. CAHB Ethics Committee Manual. If required please contact Secretary). Non Therapeutic

14. What is the potential significance of this project for improved health of the community and/or advancement of knowledge?

Information sought by the current study is to examine the following questions:

(a) Are premature infants born between November 1992 and May 1993, with birth weight less than 1500 grams and/or gestational age less than 32 weeks, who were admitted to Christchurch Women's Hospital Neonatal Intensive Care Unit developmentally delayed at 18 months of age?

(b) Data will be analysed to determine if a statistical relationship between developmental age at 18 months and selenium levels at one month of age exists.

The importance of this study is because of the little existing New Zealand data on the development of children born prematurely, and secondly because the importance of selenium at birth in premature infants has only recently become recognised, there is no data on the possible relationship between low selenium levels in premature infants and later development.

15. Briefly describe the design of the project.

Once approval is met by the ethics committees, 35 unaddressed letters informing parents of the study, it's purpose and what would be required from them, will be given to the Medical Records Office to send out to parents of eligible subjects.

The investigator's telephone number will be enclosed for parents to call with any concerns they may have of the study, either before or once consent is given. Once consent for their child's participation is given and the developmental assessment are completed, records relevant to prematurity and results of the selenium study will be accessed for correlational interpretation. A time to meet parents and child in their home before any observations of the child are commenced will be arranged by the investigator and parents. Observations and assessment of the child's developmental skills will be completed in their home so to increase participation in the study, to place the least amount of distress on the child and to increase the accuracy of developmental assessment of the child. Parents will be required to assist the investigator in encouraging the child to perform skills covering several developmental areas (cognitive, motor skills, fine motor skills and language skills). Observations and assessment of the child will be repeated after a set time period to assess the rate of skill acquisition. Letters will be sent to parents after each assessment with a list of the child's skills and skills parents should expect to see from their child in the near future. Parents will also be able to see the development of their child's skills from the report of the second visit.

16. From whom has statistical advice being sought on the size and design of the project? If a qualitative study, from whom has advice been sought? (Give name, address and telephone number).

Dr Kathleen Liberty
Education Department,
c/- University of Canterbury
Phone (03) 364-2545 &
Dr Brian Darlow
Christchurch School of Medicine
Christchurch.

16.1 What is the power of the proposed study? A brief statistical report should be included if appropriate.

The sample is small, 35 subjects or less (depending on consent), so the current study can be considered only as a pilot study.

16.2 Briefly describe how data will be analysed if using qualitative analytical techniques.

Involvement of Other Services

17. Does the project involve other services e.g. General Practice, Radiology, Haemotology, Biochemistry, Nursing, etc?

No

18. Have you discussed the project with the heads of the services involved? N/A

19. Has the Radiation Safety Committee approved the use of radiosotopes? N/A

Funding of the Project

20. Outline details of the budget including sources(s) of funding.

Education Department allows $150 costs and provides assessment materials.

21. Describe any other material benefits including fees or expenses to be received by the researcher, the host department or the host institution from undertaking this research. None

22. Will there be payments according to the number of participants recruited? If so please specify. No

23. How will subjects' expenses be covered? (e.g. travel costs, child care, user part charges).

A stamped self addressed envelope will be enclosed in the information letter to parents to return consent forms. No other expenses are expected to arise as the assessments are completed in the home and siblings are able to be present throughout the observation time.

The Patients/Subjects

24. How many patients/subjects will be involved?

No more than 35.

25. What are the inclusion criteria for the patients/ subjects/sample in the project?

Premature infants born between November 1992 and May 1993 and who had recorded selenium values at 28 days of age. Infants were less than 1500 grams and/or less than 32 weeks gestation at birth. Subjects must currently be between one year old and 18 months old.

26. What are the exclusion criteria for the patients/subjects/sample in the project?

Was not enroled in Dr Brian Darlow's selenium study.

Parents do not give consent their child be involved in the study or at any stage during the study decide to withdraw their child or previously given information from the study.

27. Will patients/subjects be:

Hospital in patients?	No
Hospital out patients?	No
Healthy volunteers?	No
Students?	No
Staff?	No
Other?	Yes

Children aged 18 months, who were involved in a previous study.

27.1 Has appropriate approval from the Dean or relevant Corporate Manager been obtained for the recruitment of volunteers, medical students or staff of the Area Health Board or volunteers?

Not needed

27.2 To your knowledge are the subjects involved in any other current research? If so, please supply details. No

28. Will patient/subject be admitted to hospital or seen as an outpatient specifically for this project?

Observations will be completed in the subject's own home.

28.1 How many visits/admissions of the patients/subjects will be required for this project? 2 visits will be made to the child's home.

28.2 Give an estimate of the total time involved for each patient/subject. Maximum of 90 minutes per visit.

Procedures

29. What procedure(s) will be carried out on patient/subjects? (Explain in terms appropriate for a lay person).

Observations of each child on a number of developmental skills set out by the Uniform Performance Assessment System (UPAS) will be completed. Parents will be present and assist in encouraging their child to perform required skills.

30. Will physical samples be taken from patient/subject? State type of sample, sample frequency, total volume and number of samples.

No

31. Will any drugs be administered? If so please complete Appendix A, Section I if registered drugs and Section II if not registered.

No

31.1 How will these drugs be provided for the subject?

N/A

32. What discomfort or inconvenience to the patient/subject do you forsee? None

33. What risks to the patient or subjects do you forsee?
None

34. Who will carry out the research procedures?
Carol Croy

35. What Facilities will be available to deal with emergencies if they arise?

If the subject or parent does not want to go on with the observations, the sessions will be ceased.

36. What arrangements will be made for monitoring adverse outcomes?
Feedback from parents.

37. Do you see any psychological risks? No

Compensation

38. What arrangements will be made for compensation of patient/subjects in the event of adverse outcomes?

Information and Consent

39. Attach a copy of the Information Sheet
It should include the following information where appropriate:

-title of project
-outline of project in lay language
-risk to subject
-side effects of any drugs
-investigations to be done
-samples to be collected
-number of visits
-whether therapeutic or non therapeutic
-any payment/expenses to patient/subject
-unless patient/subject objects, advice of participation in the study will usually be given to GP.
-compensation arrangements
-provision for onward referral if situation warrants it
-details of patient advocacy service

Attach a copy of Consent Form

Attention should be given to the following aspects when preparing a consent form:

-subjects who provide blood samples should be given the usual information about the possibility of bruising, minor discomfort etc.

-the usual formula re "withdrawing" at any time, and for any reason, without adversely affecting present or future treatment".

-contact names and phone numbers of investigators.

-consent to notify GP of subject's participation in the study.

-consent forms should be signed by investigator, patient/subject and a witness of the subjects choice.

-copy of consent form always to be retained by subject.

-that the study has been approved by the Ethics Committee of the Canterbury Area Health Board.

Verbal consent is acceptable only in exceptional circumstances. If you are not seeking written consent please give the reason.

Confidentiality and Use of Results:

40. How will information be handled to safeguard confidentiality, both during and after completion of results?

Only the investigator and Dr Brian Darlow will know those who have participated in the current study. All results will be kept under code names, not under the subject's name and only the investigator will have the list of subjects names and code names. All results and information of the subjects will be kept in a locked file.

41. Who will have access to the raw data and/or clinical records during or after the study?

The principle investigator (Carol Croy) and Dr Brian Darlow.

42. Will any restriction be placed on publication of results? No

43. Describe arrangements to make results available to patients/subjects (Wherever practicable a summary of the research findings should be given to participants).

Parents of the subjects will be sent information of the number and type of developmental skills their child has after each observation. A graph of the progress their child has made between the two observations will be sent after the second observation. Parents will also be sent a summary of the study.

44. How and when will details of the project be given to the patient's/subject's General Practitioner, and by whom? (Notification not required for all studies).

Further Ethical Issues:

45. Do you see any ethical issues arising from this project other than those dealt with elsewhere in this application? Yes

The investigator may be the first person to identify a developmental disability in the children assessed.

45.1 How do you propose to deal with them?

The investigator will not tell the parents of the developmental age of their child. This is because the investigator is not trained to make individual diagnosis of developmental delay. The Uniform Performance Assessment System is not the diagnostic instrument used in New Zealand. Such diagnosis are made by paediatricians. In this study, Dr Brian Darlow will be told of the results and will determine the appropriate follow up.

General Comments:

46. Applications are generally considered in (open) public meeting by the committee unless an "in Committee" discussion is specifically requested. Consideration "In Committee" will only be given if the reasons conform to appropriate legislation. Please indicate why open meeting discussion should not proceed. None

1. Declaration by Principle Investigator:

The information supplied above is, to the best of my knowledge and belief, accurate. I have read the guidelines for clinical research published by the Canterbury Area Health Board Ethics Committee and clearly understand my obligations and the rights of the subject, particularly in so far as obtaining freely given informed consent is concerned.

Signed_____

Date _____

2. Declaration by Head of Department or Clinical Director:

I have read the application and believe it to be scientifically and ethically sound. I am satisfied that all the necessary approvals from statisticians and the directors of any laboratories involved have been given. I approve the research design. I give my consent for the application to be forwarded to the Ethics Committee with my recommendation for its implementation.

Signed_____

Date _____

3. Declaration by (Service/Clinical/Divisional) Manager

I have reviewed the proposal for cost, resources and administrative aspects and issues regarding subject and staff involvement. The project has my approval subject to the consent of the Ethics Committee.

Signed_____

Date _____

The original and twelve (12) copies of this form and the project documentation should be submitted to the professional Advisor- Medical Services, Canterbury Area Health Board, Private Bag< Christchurch.

These forms and all other documentation must be submitted by the 1st of the month for consideration by the EC which meets on the third Monday of each month.

Please complete the attached Research Register Form and return with this application. When the project is approved by the CAHB EC an entry will be made in the Canterbury Research Register.

University of Canterbury Private Bag 4800
Christchurch New Zealand
Telephone: 03-366 7001
Fax: 03-364 2999

20 June 1994

Ms C Croy
C/- Dr K Liberty
Department of Education
University of Canterbury
CHRISTCHURCH

Dear Ms Croy

Thank you for the letter from the Canterbury Area Health Board Ethics Committee which has been added to the file.

Yours sincerely

Susan Holstein

S M Holstein (Mrs)
Secretary

UNIVERSITY OF CANTERBURY HUMAN ETHICS COMMITTEE

APPLICATION FOR REVIEW AND APPROVAL

This form should be completed in the light of the Principles and Guidelines issued by the Human Ethics Committee.

1. PROJECT NAME

ASSESSMENT OF THE DEVELOPMENT OF PREMATURE INFANTS.

Key words: up to five words for database purposes.

Premature Infant; Selenium ; Developmental Delay; UPAS

2. a. NAME OF APPLICANT: Carol Croy

TELEPHONE:

b. DEPARTMENT: Psychology

c. SUPERVISOR/COURSE:- Dr K Liberty, Education
Neville Blampied, Psychology
Dr Brian Darlow, Christchurch School of Medicine

d. OTHER INVESTIGATORS: None

AUTHORISING SIGNATURES:

Applicant.....Date.....

Supervisor/HOD.....Date.....

For Human Ethics Committee use only.

Approved.....
.....
Date.....

3. WILL THE PROJECT REQUIRE APPROVAL FROM OTHER BODIES? Yes

Yes, Canterbury Area Health Board Ethics Committee

4. IS THE PROJECT BEING EXTERNALLY FUNDED? No

A. PROJECT

The purpose of the current study is to determine if at 18 months of age children born prematurely are developmentally delayed by assessing their skill levels. There is little work completed in New Zealand in the area of long term outcomes of infants born prematurely.

If consented to by parents, two observations and assessments of the child's development and skill levels will be completed over a three to four month period.

Observations are completed in the child's home so to increase the participation rate of consent, to place the least amount of stress on the child and to give the most accurate assessment of the child's development.

5. AIM

Information sought by the current study is to be used to examine the following question:

(a) Are premature infants born between November 1992 and May 1993, with birth weight less than 1500 grams and gestation age less than 32 weeks, who were admitted to Christchurch Women's Neonatal Intensive Care Unit developmentally delayed?

Medical records relating to the birth and issues of prematurity will be accessed.

The assessment of the child's developmental level will be as set out by the Uniform Performance Assessment System (UPAS).

(b) Data will be analysed to determine if a statistical relationship between developmental age at 18 months and selenium levels at 1 month of age exists.

6. PROCEDURE

A letter informing parents of the study, its purpose and what is asked of them will be given to the Medical Records Office to be sent out to parents whose children meet the criteria for involvement in the current study. The investigator's telephone number will be enclosed for parents to call with any concerns about the study, either before consent is given or during the study. Once consent is given by parents allowing child's participation, medical records related to the birth (e.g. weight at birth, gestation age, time spent in hospital) and results of the selenium levels study will be accessed. A time to meet parents and child in their home will be made before any assessments are begun. This time allows any further queries to be addressed before any observations are started. For observation and assessment of the child's developmental skills, a time suitable for parents and at which the child is alert, will be arranged by the investigator and parents. Observations and assessment of the child require the parents to assist the investigator in encouraging the child to perform skills covering several developmental areas (cognitive,

motor skills, fine motor skills and language). However there will also be interaction between the investigator and the child.

After a three month time period the observations and assessments of the child's skills will be repeated to determine the rate of skill acquisition. Letters will be sent to the parents after each assessment with a list of skills their child has accomplished and those skills that parents should be expecting to see acquired by their child in the future, based on assessment results.

The UPAS development inventory involves a number of skills expected to be observed by children aged between Birth and 6 years of age. The skills fall into one of four groups 1. Motor skills; 2. Self Help skills; 3. Cognitive skills and 4. Language skills (see attached copy of record sheet).

7. DOES THE RESEARCH INVOLVE THE USE OF A QUESTIONNAIRE? No

B. SUBJECTS

Premature infants admitted into Christchurch Women's Hospital Neonatal Intensive Care Unit between November 1992 and May 1993. Subjects are those infants involved in a selenium study conducted by Dr Brian Darlow et al at Christchurch Women's Hospital between November 1992 and May 1993. Subjects were less than 1500g and/or less than 32 weeks gestation at birth.

8. HOW ARE THE SUBJECTS TO BE RECRUITED?

Once approval from both the University of Canterbury Human Ethics Committee and the Canterbury Area health Board Ethics Committee, letters informing parents of the study and consent forms will be given to the Christchurch Hospital Medical Records Office to be sent to parents of all eligible subjects. A stamped, self addressed envelope will be included for parents to return consent forms to the investigator. The investigator will have no knowledge of any subjects who meet the criteria until consent has been obtained fro parents.

9. WHAT INFORMATION IS BEING GIVEN TO PROSPECTIVE SUBJECTS?

See copy attached.

10. ARE THE SUBJECTS COMPETENT TO GIVE INFORMED CONSENT ON THEIR OWN BEHALF? No

Subjects are aged between 1 year old to 18 months of age, therefore parents of the children will be asked to give consent on their behalf.

11. WILL CONSENT BE OBTAINED IN WRITING? Yes.

See copy attached.

12. HOW WILL THE ANONYMITY OF THE SUBJECTS BE ASSURED?

For data presentation no subject's names will be used, instead subjects will be allocated a code name known only to the investigator. Results will be presented in a manner where the children will not be able to be recognised or traced.

C. OTHER PROJECT DETAILS

13. WHERE WILL THE PROJECT BE CONDUCTED?

The observations of children will be completed in the child's home in the presence of parents. Parents will be asked to participate in involving their children in required tasks so to assess the developmental level of the child. The study is completed in the child's home so not to distress the child and to therefore get the most accurate assessment of the child's developmental progress.

14. DESCRIBE ANY FORESEEABLE RISKS TO THE SUBJECTS

None.

15. IS DECEPTION INVOLVED AT ANY STAGE OF THE PROJECT?

Yes.

Parents of child are not told the developmental age of their child, but are given a list of skills the child currently has and what skills can be expected to be obtained by their child shortly. Parents of the child will not be given the developmental age of their child. They will be given a list of skills their child currently has and what skills can be expected to be obtained by their child. Therefore the parent will not be told if their child is developmentally delayed or not. This is because the investigator is not trained to make individual diagnosis of developmental delay. The Uniform Performance Assessment System is not the diagnostic instrument used in New Zealand.

Such diagnosis are made by paediatrician. In this study, the third supervisor, a paediatrician, will be told of the results, and can determine the appropriate follow up.

16. WILL INFORMATION ABOUT THE SUBJECTS WILL BE OBTAINED FROM THIRD PARTIES? Yes

Medical records of subjects for whom consent has been obtained will be accessed which are relevant to the birth and issues of prematurity. Parents will be asked of their child's current health status, visual problems and if their child has any hearing problems. This is to assist in choosing what skills are appropriate to be tested and whether the session should be ceased due to poor health.

D. DATA

18. WHO WILL HAVE ACCESS TO THE DATA?

The data collected will be available to the principle investigator of the study, supervisors and the child's parents. No others persons will have access to the data.

19. ARE THERE PLANS FOR FUTURE USE OF THE DATA BEYOND THOSE ALREADY DESCRIBED? Yes.

If the project is successful, publication would be considered.

20. HOW WILL THE CONFIDENTIALITY OF THE DATA BE ASSURED?

All data identifying any subject will be locked in a secure location with only the investigator having access to it.

Data available to the supervisors will have no connecting reference to the child, instead subjects are identified by code name, known only to the investigator and the third supervisor.

Regy301 HECF July 27,

University of Canterbury Private Bag 4800
Christchurch New Zealand
Telephone: 03-366 7001
Fax: 03-364 2999

24 May 1994

Ms C Croy
C/- Dr K Liberty
Department of Education
University of Canterbury
CHRISTCHURCH

Dear Ms Croy

The Human Ethics Committee apologises for the delay in responding to your application. The Committee has approved your proposal and acknowledge receipt of the amended Information Sheet. The Committee notes that you will forward a copy of the letter of approval from the Area Health Board Ethics Committee when it is received.

Yours sincerely

Susan Holstein

S M Holstein (Mrs)
Secretary

APPENDIX 2

Information Sent to Parents and a Copy of the Consent Form

Information Sheet for Parents

(Address)

1 May, 1994

Dear Parent

You and your child are invited to participate in the study of "**Assessment of the Development of Premature Infants ".**

The study is being carried out by Carol Croy as part of a Master of Arts thesis and I can be contacted at (phone number) at any time.

The aim of the study is to examine the development of premature infants who were cared for in the Christchurch Women's Hospital Neonatal Unit between November 1992 and May 1993 and whose blood selenium levels are known. We have no current information to know whether selenium levels have any relationship to outcome.

Your child's participation in this study, should you agree, would involve me observing and assessing the number of developmental skills your child has, on two separate visits approximately three months apart. This would give me greater knowledge of your child, her/his abilities and her/his progress.

All observations would be completed in your home to make your child at ease. Your participation in assisting your child in performing the skills would be required and welcomed so your child feels relaxed and will do well. You have the most knowledge of your child's capabilities.

The time required for observation will be no longer than 90 minutes at each visit and would be arranged in your free time and when your child is alert. If at any time your child becomes tired or does not appear to want to continue, the session will be stopped.

After each visit you would receive a letter with a list of your child's observed skills and what skills you may expect to see emerging. After the second visit you will be able to see from the reports the progress your child has made in even as short time period as 3 months.

If you have any concerns at all about the results of these assessments, Dr. Brian Darlow or Dr. Tim Malpas will be very happy to see your child at any early appointment in the Paediatric Outpatient Department.

I would also require access to your child's medical records looking only at the birth records, issues of prematurity and the information of the previous study.

All information about your child will be kept confidential. The project has been approved by both the University of Canterbury Human Ethics Committee and the Regional Health Authority Ethics Committee.

I would be pleased to discuss any concerns you may have about your participation in the study, or once consent is given, any queries that you may have.

You may withdraw your child at any time from the study, by notifying me at (phone number).

Thank you

Carol Croy

PLEASE KEEP THIS SHEET

PARENT CONSENT FORM

DEVELOPMENT OF PREMATURE INFANTS

I have read and understand the description of the development assessment study.

I voluntarily agree to allow my child .....
(name of child, please print)

to participate in the study, and I consent to publication of the results of the project with the understanding that anonymity will be preserved.

I also voluntarily agree to release medical records regarding my child's premature birth.

I understand also that I may withdraw my child at any time from the study, including withdrawal of any information already provided.

Name of Parent (please print).....

Signature of Parent.....

Date.....

Telephone Number .....

Address .....

.....

.....

Thank you

If you do not wish for your child to participate please return unsigned.

APPENDIX 3

Clinical Risk Index for Babies

(The International Neonatal Network, 1993)

Neonatal Medical Index

(Korner, Stevenson, Kraemer, Spiker, Scott, Constatinou & Dimiceli, 1993)

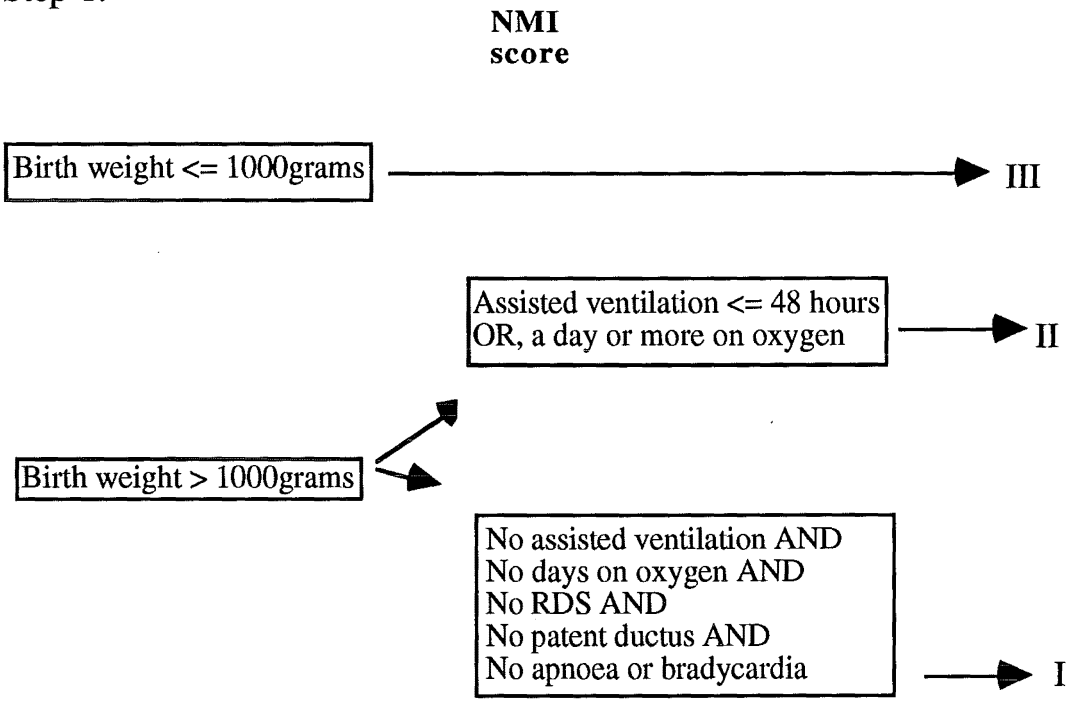
CRIB Score

Factor	Score
Birth weight (grams)	
>1350	0
851-1350	1
701-850	4
<=700	7
Gestation (weeks)	
> 24	0
<=24	1
Congentital malformations (excluding lethal malformations)	
None	0
Not acutely life threatening	1
Acutely life threatening	3
Maximum base excess in first 12 hours (mmol/L)	
> -7.0	0
-7.0 to -9.9	1
-10.0 to -14.9	2
<= -15.0	3
Minimum appropriate FiO_2 in first 12 hours	
<= 0.40	0
0.41 - 0.60	2
0.61 - 0.90	3
0.91 - 1.00	4
Maximum appropriate FiO_2 in first 12 hours	
< 0.40	0
0.41 - 0.80	1
0.81 - 0.90	3
0.91 - 1.00	5

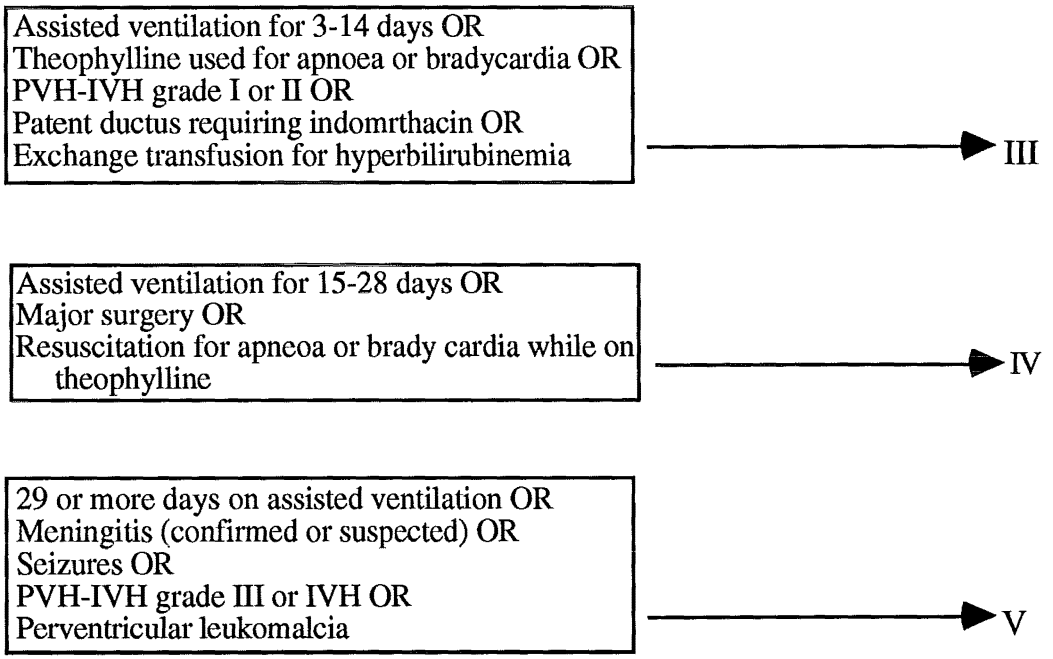
The International Neontal Network, 1993

Instructions for Calculating the Neonatal Medical Index

Step 1.



Step 2. Re-code to the highest applicable



Korner, Stevenson, Kraemer, Spiker, Scott,Constatinou & Dimiceli (1993).

APPENDIX 4

Uniform Performance Assessment System (UPAS) Skills

Uniform Performance Assessment System (UPAS) Fine Motor, Communication, Self Help and Social and Gross Motor Skills and Assessment Technique Used to Assess Skills

Fine Motor & Pre-academic

focus eyes & concentrate on string (1)	looks directly into adult's face when spoken to (1)	eyes & head follow a bright object (1)	reaches for an object held 6-8 inches away (1)
grasps easily held object when presented to her/him (1)	holds cube or toy in each hand at same time (1)	type of hand grip a: rake; b: opposition between any part of finger & thumb; c: pincer (1)	places object from 1 hand to other (1)
voluntary directed release of object (1)	build tower of 2 or more blocks (2)	puts 3 or more rings on stick (2)	puts 3 or more pegs in peg board (2)
turns 3 pages of paper book singly (2)	pounds pegs through peg board (2)	drawing characterised by continuous strokes where there at least 2 direction reversals i.e. scribbles (2)	matches 5 sets of objects (2)

Self Help & Social Skills

sucks liquid from bottle (1)	feeds self finger food (1)	drinks from cup if held (1)	independently holds cup & drinks from it (1)
brings spoon to mouth to eat (1)	loads & feeds self with a spoon (1)	passively co-operates when being dressed (1)	removes own sock independently (1)
removes unfastened coat a: with help, b: without help (3)	interacts with toys appropriately during assessment (1)		

Key to Assessment method in assessing UPAS skills
(1) Observation of skills during a natural routine
(2) test of the skill in a situation set up by the assessor
(3) parent report of skill

Haring, et al, 1981

Uniform Performance Assessment System (UPAS) Fine Motor, Communication, Self Help and Social and Gross Motor Skills and Assessment Technique Used to Assess Skills

Communication

Receptive

indicates awareness of sounds (1)	looks in direction or smiles at verbalisation (1)	turns to sound (1)	responds to own name (1)
responds to word with gesture come here (1)	responds to 'come here' without gesture (1)	responds to look here (1)	indicates at least 2 pieces of clothing & toys when told their name (2)
hear difference between d & b in similar words (2)	responds to 3 single step directions (1)	discriminate 3 non speech sounds without seeing them (2)	indicate 2 animals, foods & items in room when told their name (2)
points to 5 of their body parts when given the name (2)			

Expressive

spontaneously emits vowel sounds (1)	makes different pleasurable & non pleasurable sounds (1)	spontaneously emits consonant sounds (1)	spontaneously produces consonant-vowel combinations (ba-ba) (1)
imitates talk with sounds (1)	makes babbling noises that sound like sentences (1)	uses gestural language e.g. shakes head (1)	imitate 2 different motor actions (2)
imitate 2 non speech sounds (meow) (2)	imitate 4 different speech sounds (2)	returns 'bye-bye' without being given gestural cue (2)	asks for names of objects, real & pictured (1)
says 'no' or other appropriate protest word (1)	responds affirmatively (1)		

Key to Assessment method in assessing UPAS skills
(1) Observation of skills during a natural routine
(2) test of the skill in a situation set up by the assessor
(3) parent report of skill

Haring, et al, 1981

Uniform Performance Assessment System (UPAS) Fine Motor, Communication, Self Help and Social and Gross Motor Skills and Assessment Technique Used to Assess Skills

Gross Motor

uses left & right limbs smoothly with a wide range of movements appropriate for developmental level (1)	lifts head 90 degrees when on stomach keeping head centred (1)	brings hands to midline when lying on back (1)	centres head when lying on her/his back (1)
props self on extended arms and hands, keeping chest up when lying on stomach (1)	rolls over from her/his back to stomach (1)	child is pulled to a sitting position with head erect, no head lag (1)	lifts head without tilting or turning it, when lying on her/ his back (1)
reaches to both left and right sides when on their stomach (1)	sits without support (1)	pivots on stomach to reach an object (1)	crawls along on her/ his stomach (1)
moves from stomach to sitting position (1)	bears weight on legs with little support (1)	crawls along on hands & knees (1)	stands holding on (1)
pulls self to standing position (1)	goes from standing to sitting position without falling (1)	steps to side while holding on (1)	walks with assistance, a: 2 hands held; b: 1 hand held (1)
stands without support (1)	walks without any support (1)	pushes small chair to a directed spot (2)	turns on spot (pivots) (2)
squats without falling (1)	stoops to recover an object (1)	walks up & down 30 degree incline (2)	walks up steps holding on, 1 foot leading (2)
walks down steps holding on, 1 foot leading (2)	rolls ball (2)	kicks ball (2)	

Key to Assessment method in assessing UPAS skills
(1) Observation of skills during a natural routine
(2) test of the skill in a situation set up by the assessor
(3) parent report of skill

Haring, et al, 1981

APPENDIX 5

Sample Graph & Letter Sent to Parents.

Carol Croy

(address)

(telephone number)

(date)

Dear parents,

Thank you very much for allowing me to see Jo and for your help. It was great to see Jo walking and putting rings on the stick! I have enclosed a graph showing the total number of items Jo passed both at this visit and at the previous visit. Along the bottom of the graph is Jo's age in months at the first and second visit and up the side of the graph is the total number of skills Jo passed. Each dot on the graph represents one of my visits. Below the graph I have made a list of skills Jo learnt since my first visit.

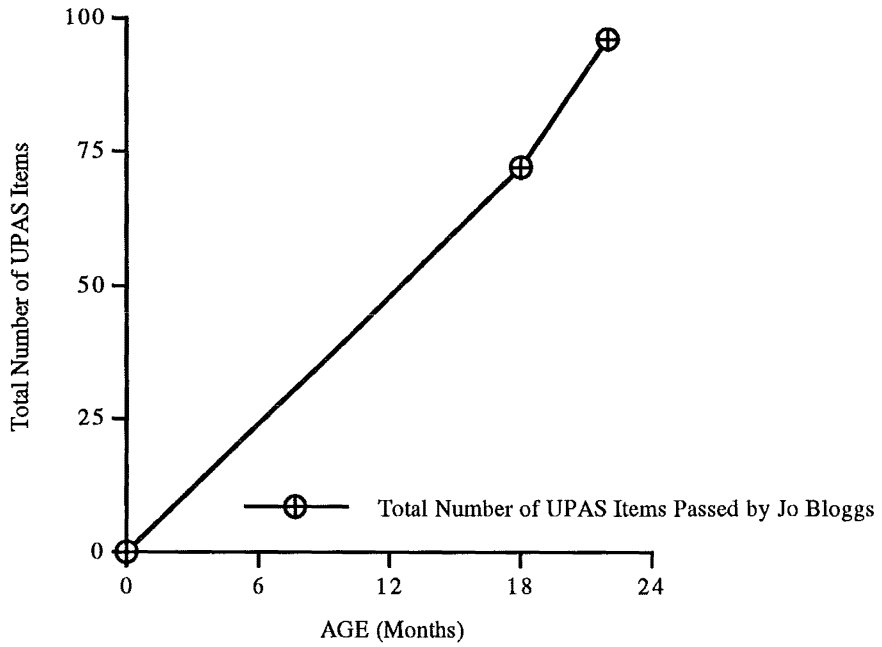
I hope to send you a summary of my study in March or April. But if you have any questions between now and then, please don't hesitate to call me on (telephone number).

Thank you again for your help and time.

Kindest Regards

Carol.

Total Number of UPAS Items Passed by Jo Bloggs, November 1994



UPAS Items Learnt by Jo Since July 1994

* stacks cubes
* puts ring on stick
* puts pegs in hole
* points correctly to doll & ball
* responds to single direction commands
* responds to body parts
* imitates 4 speech sounds
* asks for objects
* responds negatively
* feeds self with spoon
* walks down incline
* walks up & down stairs
* kicks ball

APPENDIX 6

Interview Sheet

PARENT INTERVIEW

Date _____

Child _____ Parent _____

Relationship_____ Location _____

Interview Length _____

Weight _____ Height _____

Believe that things that happen in child's life can have some effect on the rate of development.

1 Does your child have any long term health problems or illnesses?

2 Has your child been rehospitalised, or any other problems related to health or development?

3 Is your child involved in a day care or early childhood program?

4 Is there anything that you can think of that may have disrupted your child's development, for example the birth of a younger sibling, death in the family, disruption in normal routine such as shifting house?

APPENDIX 7

Developmental Rates and Ages

- **Age & Developmental Ages at the First & Second Assessment**
- **Developmental Rates at Time 1 & Time 2 (uncorrected)**
- **Averaged Developmental Rates (uncorrected and corrected)**

Table 11.

Uncorrected Age and Age Corrected for Prematurity (months) of the 23 Study Children and Developmental Ages in Individual Domains and Overall, in Months.

	Age & Developmental Ages at the First Assessment							Age & Developmental Ages at the Second Assessment						
CHILD	Uncorrected Age	Corrected Age	Fine Motor	Communication	Self-help	Gross motor	Overall	Uncorrected Age	Corrected Age	Fine Motor	Communication	Self-help	Gross motor	Overall
A	20	16	9.5	10.5	6	4.2	6	24	20	15	14	14	6	9.5
B	19.5	17	26	24	25	14.5	21	23	21.5	29	29	28	20	27
C	18.5	16.5	9.5	12.5	14	9	11	22	19	15	22.5	14	9.2	14.5
D	18.5	16.5	13	12.5	14	9	11	22	19	22	20	14	10	15
E	19.5	16	11	14	14	3.7	7.5	23.5	20	13	25	19	4.2	9.5
F	18	14.5	25	16	24.5	17	19.5	22	18.5	29	28	28	20	27
G	18	14.5	22	16	24.5	17	19	22	18.5	27	28	28	20	27
H	17.5	15.5	27	14	25.5	17	20	21	19	28	25	26	20	26
I	17.5	15.5	27	12.5	25.5	16	19.5	21	19	28	24	26	20	25
J	17.5	13.5	17	16	8	9	12	21	17	27	21.5	14	10	16.5
K	16.5	14	28	24	26	20	25.5	20.5	18	29	29.5	30.5	22	28.5
L	16.5	14	26	12.5	14	15	16.5	20	17.5	29	26	28	17.2	25
M	16	13.5	25	12.5	14	15	16	19.5	17	26	25	19	20	23.5
N	15.5	13.5	27	18	19	11.5	17.5	19	17	29	22.5	25	18.5	25
O	15.5	13.5	27	18	24.5	16	20	19	17	29	22.5	25.5	20	25
P	15	12.5	25	12.5	24.5	17	18	18	15.5	27	24	28	19.5	25
Q	14	11	15	11.5	12	10	11.5	17.5	14.5	18	21.5	24.5	13.5	19.5
R	14	11	15	11.5	12	9	11	17	14	29	29	19	12.5	22.5
S	14	11	15	12.5	12	10	11.5	17	14	25	27	19	12.5	20.5
T	18	15.5	25	18	26	15	20	21.5	19	27	25	29	19.5	25.5
U	17	14.5	27	12.5	24.5	10	15.5	21	18.5	27	25	26	20	25
V	17	14.5	25	14	24.5	11.5	16	21	18.5	26	25	26	19.5	24
W	19.5	17	27	20	24.5	17.2	21.5	23	20.5	29	22.5	25	17.8	23.5
Mean	17.09	14.46	21.48	15.02	19.07	12.77	16.02	20.7	17.9	25.3	24.4	23.3	16.2	22.2

Table 12.

Developemental Rates Calculated Using Uncorrected Age of 23 Children at the First and Second Assessment and Average Developmental Rate of the Two Assessments

	Developmental rate at assessment 1					Developmental rate at assessment 2					Average developmental rate				
Child	Over all	Fine Motor	Communication	Self-help	Gross Motor	Over all	Fine Motor	Communication	Self-help	Gross Motor	Over all	Fine Motor	Communication	Self-help	Gross Motor
A	0.30	0.48	0.53	.30	0.21	0.40	0.63	0.58	0.58	0.25	0.35	0.55	0.55	0.44	0.23
B	1.08	1.33	1.23	1.28	0.74	1.17	1.26	1.26	1.22	0.87	1.13	1.30	1.25	1.25	0.81
C	0.60	0.51	0.68	0.70	0.49	0.66	0.68	1.02	0.64	0.42	0.63	0.60	0.85	.697	0.45
D	0.60	0.70	0.68	.76	0.19	0.68	1.0	0.91	0.64	0.46	0.64	0.85	0.79	.697	0.47
E	0.39	0.56	0.72	0.72	0.94	0.40	0.55	1.06	0.81	0.18	0.39	0.56	.891	.763	0.18
F	1.08	1.39	0.89	1.36	0.94	1.23	1.32	1.27	1.27	0.91	1.16	1.34	1.08	1.32	0.93
G	1.06	1.22	0.89	1.36	0.97	1.23	1.23	1.27	1.27	0.91	1.14	1.23	1.08	1.32	0.93
H	1.14	1.54	0.8	1.46	0.51	1.24	1.33	1.19	1.24	0.95	1.19	1.44	1.0	1.35	0.96
I	1.11	1.54	0.71	1.46	1.21	1.19	1.33	1.43	1.24	0.95	1.15	1.44	0.93	1.35	0.93
J	0.69	0.97	0.91	0.46	0.91	0.79	1.29	1.02	0.67	0.48	0.74	1.13	0.97	0.56	0.50
K	1.55	1.70	1.45	1.58	0.94	1.39	1.42	1.44	1.49	1.07	1.47	1.56	1.45	1.53	1.14
L	1.0	1.57	0.76	0.85	0.74	1.25	1.45	1.30	1.40	0.86	1.13	1.51	1.03	1.12	0.89
M	1.0	1.56	0.78	0.88	1.03	1.21	1.33	1.28	0.97	1.03	1.10	1.45	1.03	.925	0.98
N	1.23	1.74	1.16	1.23	1.13	1.32	1.53	1.18	1.32	0.97	1.22	1.63	1.17	1.27	0.86
O	1.29	1.74	1.16	1.58	0.71	1.32	1.53	1.18	1.34	1.05	1.30	1.63	1.17	1.46	1.04
P	1.20	1.67	0.83	1.63	0.64	1.39	1.5	1.33	1.56	1.08	1.29	1.58	1.08	1.59	1.11
Q	0.82	1.07	0.82	0.86	0.71	1.11	1.03	1.23	1.40	0.77	0.97	1.05	1.02	1.12	0.74
R	0.79	1.07	0.82	0.86	0.64	1.32	1.71	1.71	1.12	0.74	1.06	1.39	1.26	0.99	.69
S	0.82	1.07	0.89	0.86	0.71	1.21	1.47	1.59	1.12	0.74	1.02	1.27	1.24	0.99	0.73
T	1.11	1.39	1.0	1.44	0.83	1.19	1.26	1.63	1.35	0.91	1.15	1.32	1.08	1.40	0.87
U	0.91	1.59	.735	1.44	0.59	1.19	1.29	1.19	1.24	0.95	1.05	1.44	0.96	1.34	0.77
V	0.94	1.47	.824	1.44	0.68	1.14	1.24	1.19	1.24	0.93	1.04	1.35	1.01	1.34	0.80
W	1.10	1.39	1.03	1.26	0.88	1.02	1.26	0.98	1.09	0.77	1.06	1.32	1.0	1.17	0.83

Average developmental rate = 1.0

Table 13.

Average Developmental Rates of 23 Children Using Uncorrected Age and Corrected Ages for Prematurity in Calculations

	Average developmental rates (uncorrected)					**Average developmental rates (corrected)**				
CHILD	Over all	Fine Motor	Communication	Self Help & Social	Gross Motor	Over all	Fine Motor	Communication	Self Help & Social	Gross Motor
A	0.35	0.55	0.55	0.44	0.23	0.43	0.67	0.68	0.54	0.28
B	1.13	1.30	1.25	1.25	0.81	1.25	1.44	1.38	1.39	0.89
C	0.63	0.60	.849	.697	0.45	0.71	0.68	0.97	0.79	0.51
D	0.64	0.85	0.79	0.70	0.47	0.73	0.97	0.91	0.79	0.54
E	0.39	0.56	.891	0.76	0.18	0.47	0.67	1.06	0.91	0.22
F	1.16	1.34	1.08	1.32	0.93	1.40	1.65	1.31	1.60	1.13
G	1.14	1.23	1.08	1.32	0.93	1.38	1.49	1.31	1.60	1.13
H	1.19	1.44	1.0	1.35	0.96	1.33	1.61	1.11	1.51	1.07
I	1.15	1.44	0.93	1.35	0.93	1.29	1.61	1.03	1.51	1.04
J	0.74	1.13	0.97	.562	0.50	0.93	1.42	1.22	0.71	0.63
K	1.47	1.56	1.45	1.53	1.14	1.70	1.81	1.68	1.78	1.33
L	1.13	1.51	1.03	1.12	0.89	1.30	1.76	1.19	1.30	1.03
M	1.10	1.45	1.03	0.93	0.98	1.28	1.69	1.20	1.08	1.14
N	1.22	1.63	1.17	1.27	0.89	1.38	1.85	1.33	1.44	0.97
O	1.30	1.63	1.17	1.46	1.04	1.48	1.85	1.33	1.66	1.18
P	1.29	1.58	1.08	1.59	1.11	1.53	1.87	1.27	1.88	1.31
Q	0.97	1.05	1.02	1.12	0.74	1.20	1.30	1.26	1.39	0.92
R	1.06	1.39	1.26	.99	0.69	1.30	1.72	1.56	1.22	0.86
S	1.02	1.27	1.24	.99	0.73	1.25	1.57	1.53	1.22	0.90
T	1.15	1.32	1.08	1.40	0.87	1.26	1.45	1.19	1.53	0.95
U	1.05	1.44	0.96	1.34	0.77	1.21	1.66	1.11	1.55	0.89
V	1.04	1.35	1.01	1.34	0.80	1.20	1.56	1.16	1.55	0.92
W	1.06	1.32	1.0	1.17	0.83	1.21	1.50	1.14	1.33	0.94
Mean	1.02	1.26	1.04	1.13	0.78	1.18	1.47	1.21	1.32	0.90

Average developmental rate = 1.0